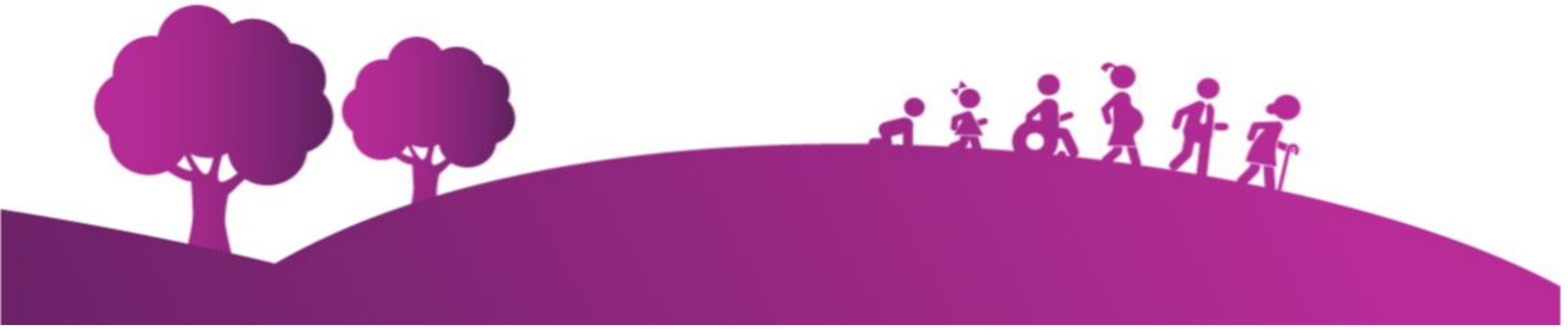
NORTH EAST AND NORTH CUMBRIA
Congenital Heart Disease Network

Annual Report 2020/21

August 2021



Document History

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Owner	NENC CHD Network Board

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Date	**Revision Summary**
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Contributors to current version		
Role	**Name**	**Notes**
Chairperson	Jonathan Wyllie	
Clinical Director	David Crossland	
Adult Lead	Louise Coats	
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Network Lead Nurse	Kaye Walsh	
Adult Nurse Specialist	Lorna Carruthers	
Paediatric Nurse Specialist	Deb Lawson	
CHUF Representative	Charlotte Campbell	

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Foreword

This has been a particularly hard time for all clinical providers but even more difficult for our patients and their families. The network has tried to provide up to date advice and support both locally and through the website and national links. Clearly both services and network plans have been affected by the pandemic but despite that we can be pleased with the areas of achievement which are highlighted in this report.

Education continues to be an area which is going from strength to strength, appreciated by the widening groups of colleagues who are accessing it. One of the few benefits of a pandemic is the availability of online access.

Research is also an area which is continuing to develop and looking to involve as many as possible in answering both medical questions but also striving to obtain data about the lived experience of those with congenital heart disease. This is essential for the network to act in improving services across the region.

Pleasingly, more are accepting the fact that congenital heart disease is a continuum from fetal diagnosis, through birth to paediatric care and then, with increasing operative and interventional techniques, through to adulthood living independently with congenital heart disease. This is, of course, obvious but it is important that we all make these points to NHS planners whenever the opportunity arises. Only then will we avoid patients lost to follow-up or facing avoidable problems because they become invisible to NHS services.

Despite so many calls on our time and with so much pressure on the NHS it is increasingly important that we maintain our drive and commitment to this young network. There are changes likely ahead and both opportunities and challenges in the future. I would like to thank all who have and are contributing to the care provided across this network. Please keep it up and remain committed to improving things together. With that in mind, Terry and myself hope to meet up with all peripheral services and their management teams throughout the next year. I look forward to meeting you then even if still behind a mask or a screen.

Finally, I would like to personally thank all the network team for their work and support through the past year.

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 Specifications[1] 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

To provide high quality, equitable care for congenital heart disease patients wherever they live within our region; provided closer to home when possible, ensuring seamless transition between fetal, paediatric and adult services and providing a holistic approach to care.

Network Objectives

- 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.

Network Management Team

The network management team was formerly established in January 2020, comprising of the Network Chair (Jonathan Wyllie), Network Clinical Director (David Crossland), Network Manager (Terry Phillips), Network Lead Nurse (Kaye Walsh) and Network Administrator (Rebecka Nordstrom). Our network benefits from the expertise of a Paediatric Clinical Lead (Abbas Khushnood), an Adult Clinical Lead (Louise Coats) and data manager (Gwen Taylor).

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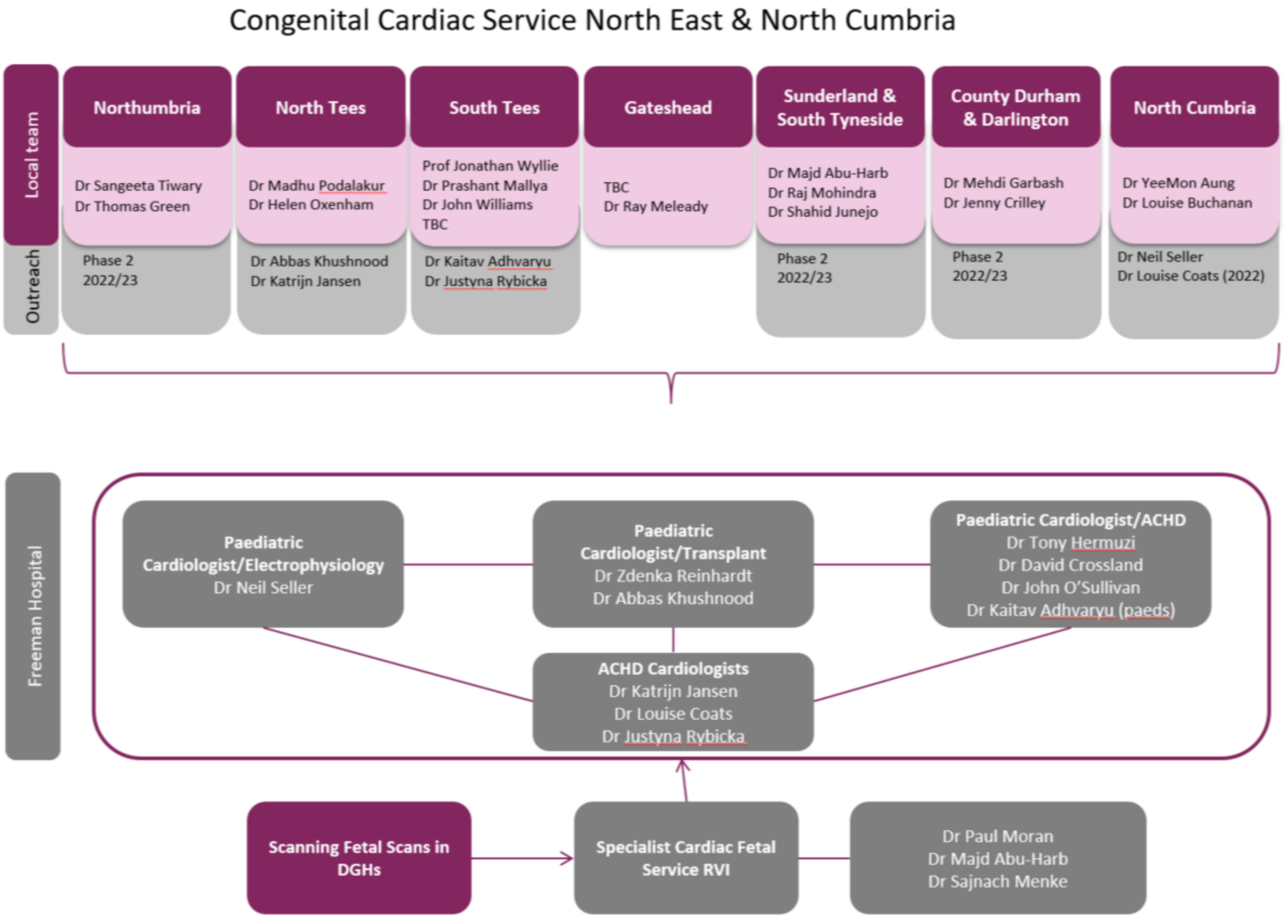
[1] https://www.england.nhs.uk/wp-content/uploads/2018/08/Congenital-heart-disease-standards-and-specifications.pdf

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.


Congenital Cardiac Service North East & North Cumbria

	Northumbria	North Tees	South Tees	Gateshead	Sunderland & South Tyneside	County Durham & Darlington	North Cumbria
Local team	Dr Sangeeta Tiwary Dr Thomas Green	Dr Madhu Podalakur Dr Helen Oxenham	Prof Jonathan Wyllie Dr Prashant Mallya Dr John Williams TBC	TBC Dr Ray Meleady	Dr Majd Abu-Harb Dr Raj Mohindra Dr Shahid Junejo	Dr Mehdi Garbash Dr Jenny Crilley	Dr YeeMon Aung Dr Louise Buchanan
Outreach	Phase 2 2022/23	Dr Abbas Khushnood Dr Katrijn Jansen	Dr Kaitav Adhvaryu Dr Justyna Rybicka		Phase 2 2022/23	Phase 2 2022/23	Dr Neil Seller Dr Louise Coats (2022)

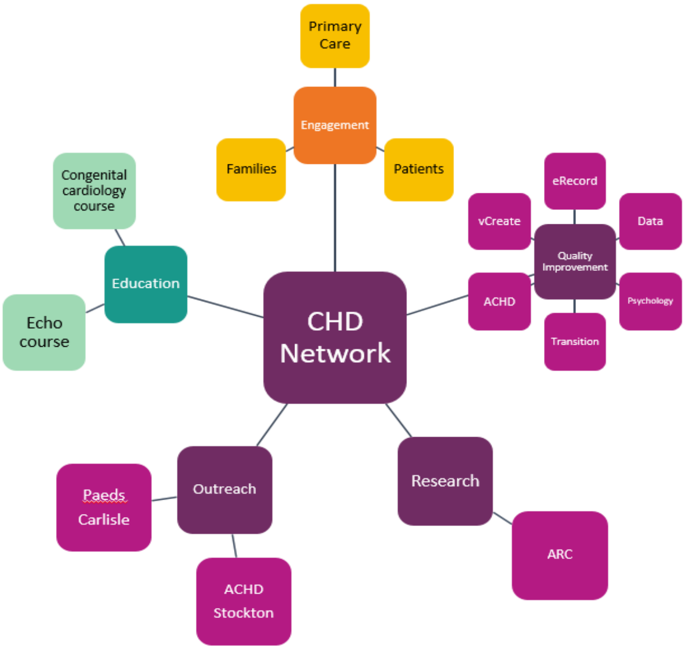
Achievements

The last year has been understandably challenging in engaging with teams across the Network while the pandemic continues to test teams to their limits. Nevertheless, as a Network we have managed to make progress with some objectives of our 2020/21 work plan which are discussed below.

Network appointments

We have the pleasure of welcoming Professor Ahmet Fuat to the Network Board as primary care representative, and Dr Emily Bell as the Network clinical psychology representative.

We would also like to welcome Rebecka Nordstrom our new administrator to the Network team.



Outreach

Middlesbrough

Both the paediatric and adult outreach clinics at James Cook University Hospital have restarted supported by Dr Kaitav Adhvaryu and nurse specialist Deb Lawson, and Dr Justyna Rybicka and nurse specialist Lorna Carruthers respectively.

Stockton

Dr Katrijn Jansen has started a parallel adult outreach clinic with Dr Helen Oxenham at University Hospital of North Tees in Stockton. This clinic runs every 7 weeks and 1 in 3 clinics will be held at University Hospital of Hartlepool.

Carlisle

A new paediatric outreach clinic in has been set up in Cumberland Infirmary, Carlisle. This is a monthly clinic run by Dr Seller and accompanied by a nurse specialist when needed (Network funded).

Engagement

Young Persons Group https://nenc-chdn.uk/young-persons-group

The Network team have had a number of discussions with young patients in order to establish a Young Persons Group. The group will include patients aged 12 – 18 years old living with congenital heart disease with the purpose to influence decisions and service planning that will impact on their future.

This public group is for young people to participate in discussions, critique relevant information and documentation, meet others and have their voice heard about what matters to them. The group forum makes sure we have a balanced, well represented view of CHD services for young people, both positive and negative.

We are hoping to launch this group following an engagement event in September. Facilitated by TinArts the event will be an opportunity for young people to explore and create by taking part in a graffiti project. The completed work will be displayed at centres across the region and on the Network website.

Patient and Family Engagement https://nenc-chdn.uk/patient-engagement-group

CHUF have very generously supported the Network in providing Teddy Bears for new patients seen at the Freeman Hospital and at outreach clinics. The bears will provide a means of raising awareness of CHUF and the Network, and signpost families on where to access further support and information.

Hello my name is CHUFY bear,

Please look after me and take me home. I have been specially made by my friends at CHUF. CHUF have asked me to let you know that we think you are amazing!

CHUF are working with the North East and North Cumbria Congenital Heart Disease Network (NENC CHDN) to help provide care closer to home for amazing Heart Heroes just like you. They have asked me to tell you that they are always there to support you should you need any help or advice. You can find out more about CHUF and the NENC CNDH on their websites.

Thank you for taking care of me, I'm sure we will be the best of friends.

Chufty

CHUF is a registered charity in England and Wales No 1160831

We are working with CHUF and Close House to host a golf day for dads with children with CHD. The event will provide an opportunity for fathers to share their experience with each other and with the team, and provide information on how we can develop CHD services for patients and families.

It is also an opportunity to raise awareness of CHUF and the Network and signpost families on where to access further support and information.

Close House have agreed to waive the costs of hosting this event and are only charging for the provision of refreshments.

FREE Dad's Golf Event at Close House

Sunday 22nd August 10am – 4pm

☑ Join us at Close House for a day of golf and meet a PGA golf professional.
☑ Meet the CHD Network team.
☑ Share your experience of using CHD services in the North East & North Cumbria.
☑ Help us shape the future of CHD services in the region.
☑ Or just come along to hit a few golf balls for FREE!

Close House PGA Academy and Driving Range suit golfers of all ages and abilities, from beginner to the more advanced.

First, come and see their Toptracer Technology, a new range system helping golfers monitor and perfect their golfing performance. Download the free Toptracer range app, sync your phone to the screens at the Academy & monitor your golfing swing every time.

Then have a round on their new 9-hole Yearling course, an excellent opportunity to sharpen your short game.

This event is supported by Close House www.closehouse.com, CHUF www.chuf.org.uk and the NENC-CHD Network www.nenc-chdn.uk. The event will take place Covid permitting and it's limited to 20 spaces, so be quick to email nuth.enquiries-nencchdn@nhs.net with your queries and registration!

nenc-chdn.uk

Freeman Hospital, Freeman Rd, Newcastle Upon Tyne, England NE7 7DN, United Kingdom

Primary Care Engagement

The Network have partnered with the Physical Health and Long Term Conditions Clinical Network to host a Primary Care Engagement event. It is an opportunity for healthcare professionals working in primary care to find out more about the Clinical Networks in the North East and North Cumbria, meet the teams and learn how we are here to support them in the care of patients with long-term conditions and complex needs.

Our ambition is to join up primary and secondary care provision, we want to hear from primary care colleagues as we work towards more integrated healthcare provision.

CHUF

The Network continue to work closely with CHUF to support cardiac care across the region, inspire innovation and improve care. CHUF have been extremely supportive of the Network team as the Network matures, working together with to establish a patient engagement group to support children and families throughout their CHD journey and into adulthood. Examples of our collaboration can be found without this annual report as well as the specific projects outlined below.

Mental Health & Wellbeing Review

In partnership with CHUF the Network are reviewing the psychology provision across the region. Currently CHUF provide funding to support psychology services for CHD children at South Tees and Carlisle.

There is robust evidence highlighting the psychological impact of living with and receiving treatment for cardiac conditions. Following discussions with a number of families in our region, discussions with other CHD networks and feedback from children and young people groups, we have extended the review to include a wider range of support for CHD patients. The review will consider a number of elements including psychology, youth workers, social care, peer support, social prescribing and exercise & lifestyle practitioners.

The review aims to design a comprehensive holistic support offering tailored to the needs of the patients in our region. The review is currently at the scoping stage and we encourage teams from across the region to put forward their ideas and aspirations for a mental health and wellbeing service for CHD the region.

ECHO machine audit

The use of ECHO machines outside of main cardiac centres has many benefits to the peripheral hospitals. Babies and children including newly born babies in maternity units are diagnosed more accurately, locally and within a shorter time frame. Wireless ECHO images can be sent very quickly to the specialist centre for quicker diagnosis without the need for families to travel long distances, thereby reducing pressure on the specialist centre.

CHUF currently fund ECHO machines at James Cook Hospital, Sunderland Royal Hospital and Cumberland Infirmary.

The Network are working with CHUF on an audit to identify the current and future need for ECHO machines across the region with the aim of outlining a succession plan and providing more sustainable resources to teams across the region.

Quality Improvement

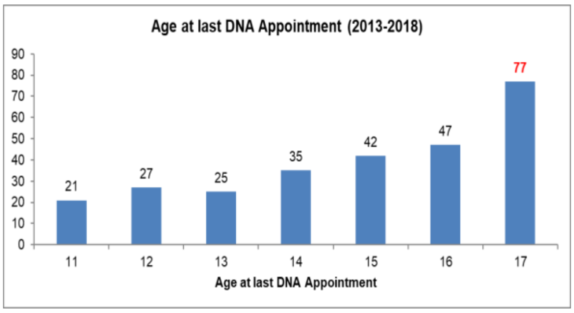
Service Improvement Project Transition Lost to Follow Up – Gwen Taylor

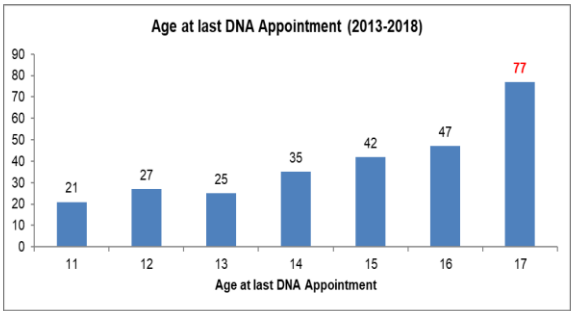
Gwen Taylor carried out a project to investigate the number of patients who have been lost to follow up during transition to adult services. Transition patients are being lost from paediatric cardiology to congenital adult services and there is no alert system currently in place to inform transition nursing teams when children reach the age of 11.

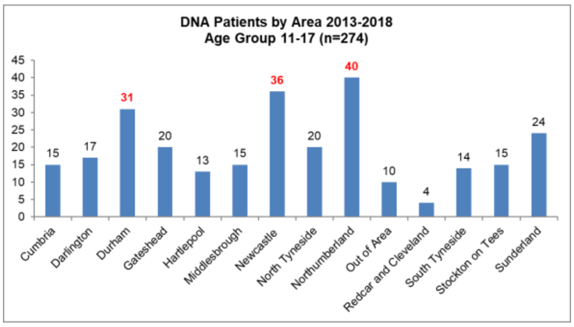
We have the opportunity to highlight children approaching transition age via alert flag to transition team and create a form in eRecord to capture transition data.

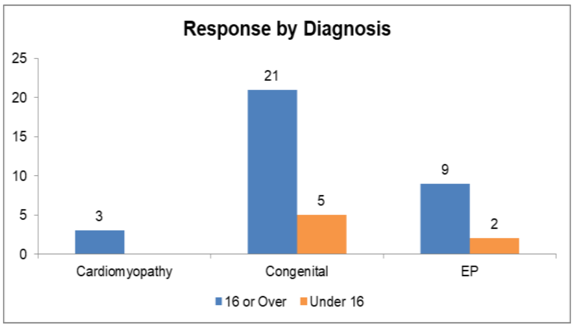
The project set out to identify patients lost to follow up at the Freeman Hospital using out-patient appointment data 2013-2018. The data was filtered by postcode area, gender and age group (11-17 years) highlighting the last appointment with non-attendance. All DNA appointments and previous clinic letters were examined to group by diagnosis and identify possible reasons for DNA (i.e. incorrect correspondence address or possible administration errors with appointment scheduling).

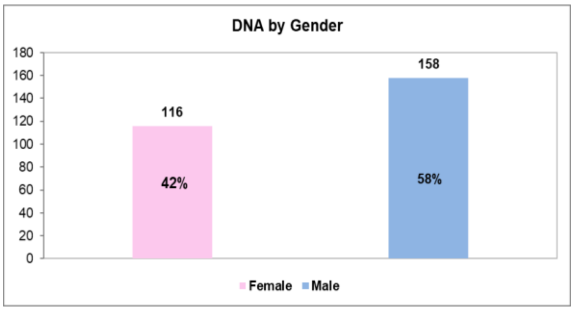
The findings identified 274 patients aged 11-17 years as lost to follow up in the 5 year period (male 158, 58%; female 116, 42%).





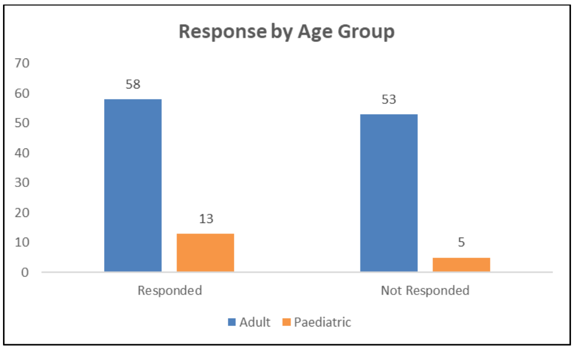


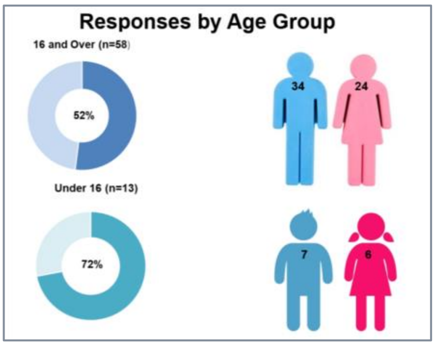




Following the review of out-patient activity, and excluding patients not required for follow up, 129 initial letters were sent to patients asking them to make contact.

- 111 patients aged 16 or under, 18 patients under 16
- 73 second request letters sent





The overall response rate was 55%; 71 patients in total, 58 aged 16 or over and 13 paediatric patients. Forty patients requested a future appointment (31%); 32 aged 16 or over and 7 paediatric patients.

The team are working with information services to make changes to the hospital eRecord system to create an alert when children move to transition and improve on-line recording of transition information. A working group is in place to identify transition patient's needs, patient involvement and improvement to services. The outcome of this work and further developments will be shared with the Network Board.

vCreate

vCreate is a secure clinical video technology to support diagnosis, management and decision-making processes. The Network are running a pilot of the software across 4 units in the region, including the Freeman Hospital.

The project will investigate if vCreate is an effective tool;

- For sharing echocardiograms, as well as other test results, between clinical teams
- In enhancing clinical decision making
- For sharing patient video experiences/assessments
- In alleviating parental/family concerns by sharing patient videos

The outcome and success criteria include;

- Reduce unnecessary appointments
- Reduce the number of patients coming for outpatient appointments
- Increase communication and information sharing across the network

The project will run for 6 months and will include teams in Newcastle, North Tees, South Tees and Cumbria and we are hoping to start in November 2021.

Education

The education programme continued with virtual meetings and webinars including;

- Patient journey
- Life in a goldfish bowl: The VAD patient journey
- The complexities and challenges of the Fontan circulation
- Congenital Heart Disease-The importance of nutrition and diet
- The unstable cardiac neonate
- CHD pharmacology
- ECG and arrhythmia live simulation

A particular achievement was the introduction of a live simulation in to the webinar session on ECG and arrhythmia.

This year also seen the introduction of booster sessions and lunchtime drop-in sessions including;

- Inherited cardiac conditions – Julie Goodfellow
- Congenital heart disease and genetic conditions – Lorna Carruthers
- Septal defects – Debs Richardson
- Ebstein anomaly – Lorna Carruthers
- Aortic stenosis & Advancing surgical techniques – Lorna Carruthers
- Coarctation of the aorta – Deb Lawson

- Fontan – Deb McParlin
- Transposition of the great arteries TGA /congenitally corrected TGA – Lorna Carruthers
- Tetralogy of Fallots – Sara Lane
- Normal heart – Kaye Walsh

Video presentations can be found on out YouTube channel and our website.

Study days – nurses, ODPs and allied healthcare professionals

In May the team hosted an introductory Teams session to describe a range of common congenital heart lesions and the issues that they may cause in children and adults.

We are delighted to share the development of our two-day Paediatric congenital 2D cardiac echocardiography course to be hosted at the Freeman hospital. The first course will be delivered in November 2021 and will be aimed at enhancing understanding of congenital echocardiography at a basic level of experience. It covers all primary applications of paediatric congenital cardiac echocardiography, providing comprehensive learning through case-based lectures and practical hands-on sessions with volunteer paediatric patients.

Network Budget

The current Network budget only covers Network team salaries, however due to the vacant administrator post there was an underspend in the budget. The Network has therefore been able to fund a number of initiatives which will benefit CHD patients across the region.

Clinical time

The Network has funded the PAs needed to set up the new paediatric outreach clinic in Cumberland Infirmary, Carlisle. This is a monthly clinic run by Dr Seller and accompanied by a nurse specialist when needed.

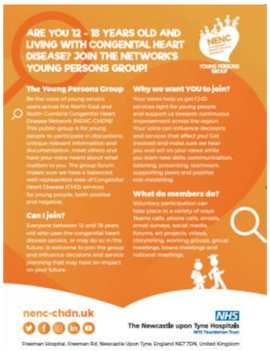
New weekly nutrition clinics run by a nurse specialist at the Freeman Hospital have been funded for 12 months. Once established at the level 1 centre these clinics will be rolled out across the region alongside outreach clinics.

Hardware

The Network have purchased android tablets to be used during patient consultants at outreach clinics. The tablets will be used to explain diagnoses with patients and families, and point them towards further information about their condition.

Marketing

In order to raise awareness of the Network, the team have engaged with Inspired Agency to create a Network logo and associated branding. These include posters, leaflets, mugs and pens, and a conference banner to use at roadshow events across the region.


ARE YOU 12 - 18 YEARS OLD AND LIVING WITH CONGENITAL HEART DISEASE? JOIN THE NETWORK'S YOUNG PERSONS GROUP!

The Young Persons Group

Be the voice of young service users across the North East and North Cumbria Congenital Heart Disease Network (NENC-CHDN)! This public group is for young people to participate in discussions, critique relevant information and documentation, meet others and have your voice heard about what matters to you. The group forum makes sure we have a balanced, well represented view of Congenital Heart Disease (CHD) services for young people, both positive and negative.

Can I join?

Everyone between 12 and 18 years old who uses the congenital heart disease service, or may do so in the future, is welcome to join the group and influence decisions and service planning that may have an impact on your future.

Why we want YOU to join?

Your views help us get CHD services right for young people and support us towards continuous improvement across the region. Your voice can influence decisions and services that affect you! Get involved and make sure we hear you and act on your views while you learn new skills: communication, listening, presenting, teamwork, supporting peers and positive role modelling.

What do members do?

Voluntary participation can take place in a variety of ways. Teams calls, phone calls, emails, email surveys, social media, forums, art projects, videos, storytelling, working groups, group meetings, board meetings and national meetings.

nenc-chdn.uk

The Newcastle upon Tyne Hospitals NHS Foundation Trust

Freeman Hospital, Freeman Rd, Newcastle Upon Tyne, England NE7 7DN, United Kingdom


PATIENTS & FAMILIES, JOIN THE PATIENT & FAMILY ENGAGEMENT GROUP!

The Patient & Family Engagement Group

This public voice group participates in discussions, critiques relevant information and documentation and champions the voice of service users across the North East and North Cumbria Congenital Heart Disease Network (NENC-CHDN). It provides a balanced view of Congenital Heart Disease (CHD) services, both positive and negative.

Can I join?

Everyone who uses the service or may do so in the future can join the group. Patients, families, carers etc. We aim to have representation from a variety of subgroups across the patient population.

Why we want YOU to join?

Your views should inform service development, this helps us get services right for patients and supports continuous improvement across the North East and North Cumbria. We recognise and value the contribution of those who use the CHD services in shaping the future health care provision in our region across the organisations.

What do members do?

Participation can take place in a variety of ways. Email surveys, social media, forums, working groups, group meetings, board meetings and national meetings.

nenc-chdn.uk

The Newcastle upon Tyne Hospitals NHS Foundation Trust

Freeman Hospital, Freeman Rd, Newcastle Upon Tyne, England NE7 7DN, United Kingdom


Patients with Long Term Conditions and Complex Needs

A Primary Care Engagement Event

Wednesday 29th September 18:30 - 19:30 on Teams, see https://chdnnenc.eventbrite.co.uk

Organisers: NENC-CHDN & the Physical Health and Long Term Conditions Clinical Network.

nenc-chdn.uk

NHS England

The Newcastle upon Tyne Hospitals NHS Foundation Trust

Freeman Hospital, Freeman Rd, Newcastle Upon Tyne, England NE7 7DN, United Kingdom


NENC Congenital Heart Disease Network

OUR VISION

OUR STRATEGY

CARE CLOSER TO HOME

SCAN THE BARCODES BELOW TO READ MORE

Events

The Network budget is also supporting Dad's golf event at Close House with CHUF in August and the Young Persons Summer event with TinArts in September, if covid restrictions allow.

Training and conferences

The following training and conference attendance was supported by the Network budget;

- Fibroscan training for 3 nurse specialists
- 10 places on the Congenital Cardiac Nurses Association (CCNA) Virtual Conference held on 10 June 2021
- CCNA Membership
- 20 places on the leadership course 'Covid 19 - Leading in a pandemic'

Under the spotlight

Paediatrician with Expertise in Cardiology (PEC)

University Hospital of North Tees

Dr Abbas Khushnood started the outreach clinic at University Hospital of North Tees in #### where he works alongside Dr Madhu Podalakur and Dr Subhan Christudas, both of whom are consultant paediatricians.

The clinic started as an initiative to help with the waiting list at the Trust and has developed in to a robust outreach model to support the development of the Paediatricians with an Expertise in Cardiology (PEC) role across the region. Abbas runs a parallel clinic alongside Madhu and is available to consult on a patient if necessary.

These clinics have further benefited from the expertise of Subhan who runs a heart murmur clinic in order that patients can be appropriately triaged. This ensures that patients with innocent murmurs are not referred directly to the CHD clinic freeing up availability of both Abbas and Madhu.

James Cook University Hospital

Despite the difficulties of the 20/21 year Drs Jonathan Wyllie and Prashant Mallya provided 10 cardiac telephone clinics and 88 face to face clinics for children with suspected or actual congenital heart disease to be seen locally. The numbers were reduced due to the need for PPE and extra spacing of patients but still more than 650 face to face cardiac clinic places were offered as well as 120 telephone follow-up appointments. Non-attendance has run at less than 5%.

Also during this time Dr Kaitav Adhvaryu took over the regional outreach clinic from Dr David Crossland. This clinic has now reopened and is again providing tertiary cardiology follow-up to patients and families and support to the local PEC team

ACHD

Our adult nurse specialist, Lorna Carruthers, has been liaising with CHUF on supporting adults with CHD during their stay at the Freeman Hospital. CHUF are working with the Newcastle Hospital charities to provide accommodation and beverage bays for adult patients and their families.

CHUF are running poster and website campaigns promoting their support of the adult service which aligns with their vision of providing lifelong care for heart patients.

CHUF are also providing funds to support additional monitoring and purchasing ECG and blood pressure monitors for patients. They have also been provided access to the hotel accommodation for families which they use for paediatric patients.

The charity has been providing the ACHD nurse specialists with a float during the covid pandemic and will continue in the future as well as providing access to the ice cream van visits and winter activities that they provide for the paediatric ward.

Lorna has gone above and beyond in caring for the holistic needs of her patients, so much so that she recently arranged an outing to the seaside for one of her patients who had been an inpatient at the Freeman for over 200 days.

A much needed and very welcome break from being in a hospital environment.

* patient consent obtained for use of photograph

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.

Network work plan 2021/22

- Patient & Family engagement
  - Young person's working group
- Stakeholder engagement
  - Primary care
  - Engage with ICS
- Outreach clinics
  - Carlisle and North Tees
  - Darlington and South Tyneside/Sunderland
  - Particular emphasis on adult CHD
- Education
  - Webinar series
  - Online videos
  - Visiting consultants
  - Promote the PEC role
- Governance
  - Network governance/audit lead
- Transition
  - Transition lead
  - Identify a process
  - Engage with families and young people
- Communication
  - Review current processes
  - Review MDT arrangements
  - Virtual consultations
  - vCreate Project
  - Clinical case review meetings
- Data/information sharing
  - CHD database
  - Access to information
  - Emergency healthcare plans
- Research
  - ARC Project

Peripheral centre visits

At the launch of the Network we had great ambitions to visit each centre and understand the needs and ambitions of each service. Although the pandemic has prevented this, we have been working hard to gather information and create a mechanism to achieve this.

During November, the Network Chair and Manager will be visiting Trust executive teams to discuss the ambitions and objectives of the Network, outline our 5-year Strategy and understand their priorities for delivering a CHD service locally.

Over the past year it has become evident that workforce and facilities are a negative factor in the development and improvement in CHD services within the Level 1 centre and within the centres of the Network.

Over the next 12 months the Network Manager will work with Trusts to identify priorities from the national standards, recognise problem areas and understand the barriers to developing CHD services locally. We feel the following are the key recommendations;

- Develop the PEC (paediatrician with expertise in cardiology) role locally (20% job planned for CHD patients)
- At least one consultant cardiologist with an interest in ACHD
- Link nurse role – nurse with a special interest who will liaise with the L1 centre (0.25WTE)
- Cardiac physiologist trained in CHD echocardiography
- Attendance at MDT meetings 6 times per year (job planned)
- Attendance at Network Board meeting at least once per year (job planned)
- Clinical review meetings twice per year
- Endocarditis audit
- Reporting and discussion of adverse incidents

ACHD Review

Together with the Level 1 centre the Network will be reviewing the adult CHD services within the Freeman Hospital to address the areas highlighted by the NHS England CHD Service review. The objectives of the review are to improve services for adult CHD patients with long inpatient stays, particularly those relating to the non-clinical aspects of their care.

The NHS England Peer Review made the recommendations regarding specialist nursing provision, psychological support, education and patient feedback, and these will be considered during the review. In addition to these we will review ward environment and facilities, relative accommodation, medical staffing and wider care and support for patients and families.

In addition to the above, there needs to be plans in place for the ACHD service once the co-location of the paediatric CHD service comes to fruition in 2023/24.

With the ACHD service at the Freeman Hospital in a stronger more sustainable position, the Network can continue to make improvements across the network in supporting ACHD teams in the regional centres. This work will align with other work currently supported by the Network team for outreach, transition and psychology, and will form part of the 5-year strategy for the NENC-CHD Network.

Patient and Family engagement

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.

We will continue to build on the work currently underway with engagement events to create the Young Person's Group and Patient & Family Engagement Group. The network lead nurse has spoken to a number of patients and families and has identified a number of people interested in joining these sub-groups. We will report on developments through the year at our Network Board meetings.

Outreach Clinics

The next phase (2022/23) of outreach clinics will focus on supporting adult CHD patients;

North Cumbria – We are investigating the possibility of setting up an adult outreach clinic with a focus on aortopathy, either within a hospital setting or within the community/primary care.

County Durham & Darlington – monthly clinics at Bishop Auckland Hospital

Northumbria – monthly clinics alternating between Wansbeck and North Tyneside General Hospitals

South Tyneside and Sunderland – monthly clinics alternating between Sunderland Royal and South Tyneside General Hospitals

Multi-disciplinary Team Meetings

The Network will be reviewing the MDT processes to ensure comprehensive representation from all Trusts in the region. The joint cardiology–cardiothoracic multi-disciplinary team meeting is held weekly on a Wednesday afternoon at the Freeman Hospital.

The Network Administrator is actively involved in arranging these meetings and in designing the underlying processes. The Network team will feedback at Network Board meetings.

Primary Care Engagement

In partnership with AHSN the Physical Health and Long Term Conditions Clinical Network (PHLTC) we will be hosting a Primary Care engagement event on 29th September. The event will be chaired by Dr Ahmet Fuat and is an opportunity to find out more about the Clinical Networks in the North East and North Cumbria, meet the teams and learn how we are here to support primary care in the care of patients with long-term conditions and complex needs.

Our ambition is to join up primary and secondary care provision, we want to hear from primary care teams and for them to be involved in the Networks as we work towards more integrated healthcare provision.

The event will also discuss the issues and challenges around prescribing and medication use in patients with congenital heart disease and be an opportunity to hear what matters to teams when caring for patients with complex health needs.

Following this event we hope to set up a Primary Care subgroup with the PHLTC clinical network to continue this engagement and drive service improvements for patients with long term conditions and complex needs.

Education

Educational programme

We will continue to develop our educational programme to meet the needs of the units across the region. The rapid evolution and integration of digital platforms has enabled the success of the virtual learning programme to date. Feedback from attendees suggests that face-to-face learning is of value and must not be completely disregarded for future education events. When we are able to do so the education events will be available both face-to-face and virtual to allow maximal learner satisfaction.

The initial approach to deliver sessions to the multi professional teams across the region has since evolved into a more bespoke offer focussing on professional groups to ensure the best outcomes for the learners.

Working in collaboration with regional networks, our educational offer will ensure equal access to education and training in all centres for all healthcare workers. We have successfully contributed to a number of joint education programmes within the region and nationally with our network partners.

Congenital cardiac course

We have embedded congenital heart disease and heart failure management into regional education programmes. The network lead nurse has designed a congenital cardiac course and we are in the early stages of having this course formally adopted by Newcastle upon Tyne hospital Skills academy. This relationship will provide an academic platform for the educational content and support for learners. The course content will be delivered by experts in congenital heart disease. This lifespan programme will attract healthcare professionals from a range of roles and provide detailed knowledge and skills in the management of patients with congenital heart disease and failure. Feedback from a regional survey has suggested that this course is attractive and would be valued. We are hopeful that this project will be ready for the first candidates to sign up in 2022.

Paediatric Congenital Cardiac 2D ECHO course – 20-21st November 2021

In conjunction with Newcastle Skills Academy the Network are running a two-day course aimed at enhancing understanding of congenital echocardiography at a basic level of experience. It covers all primary applications of paediatric congenital cardiac echocardiography, providing comprehensive learning through case-based lectures and practical hands-on sessions with volunteer paediatric patients.

The course is suitable for anyone involved in care and management of CHD disease (neonates, infants and children) including consultants and trainees (paediatrics, neonatology, paediatric cardiology, ACHD, cardiac surgery, cardiac anaesthesia and intensive care), paediatricians with expertise in cardiology (PECS) and cardiac physiologists.

Nurses, ODP and Allied Health Professionals session – October 2021; February 2022

Following on from the introductory session in May, the October session will focus on recognition and stabilisation of the patient presenting with heart problems. In February we are planning to host a face-to-face engagement and education day to build on these two events.

These sessions will also be run for consultants (November 2021) and trainees (January 2022).

CHD Database

Following a number of meetings and discussions this year we are exploring a number of avenues to start work on compiling a database of patients with CHD across the region.

We have applied for a data extract from NCARDRS. The Head of Registration for NCARDRS North is also involved with the NW Congenital Heart Disease Network and has established an MOU between NHS Trusts and the Network in order to share data. We are embarking on a similar exercise here in the North East and North Cumbria.

Alongside this, the Network team have approached each Trust to share patient lists. Following discussions with information governance leads we are completing a Data Protection Impact Assessment to enable data sharing across network.

The Future of ODNs

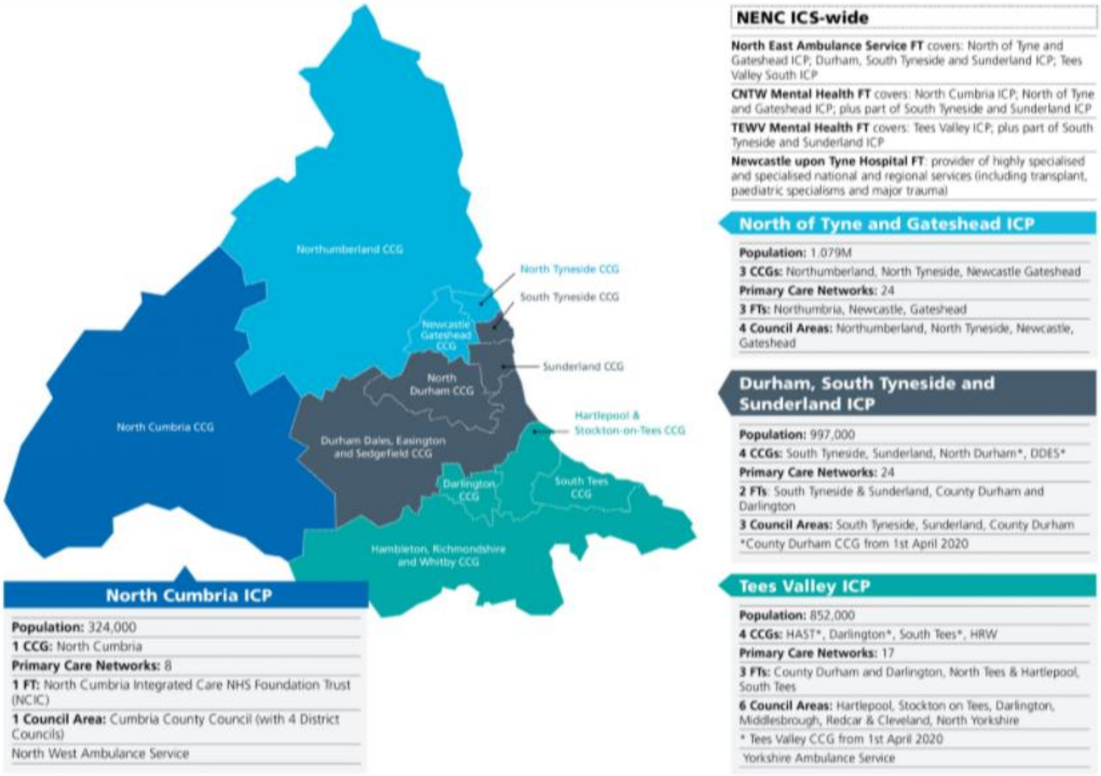
The NHS Long Term Plan[4] set out a route map for how health and care will be more joined up locally around the needs of the population. During 2021 this will be further developed by the legislative reforms proposed for Integrated Care Systems (ICSs). NHS England published details[5] of how systems and their constituent organisations will accelerate collaborative ways of working and establish ‘place-based’ partnerships.

During the pandemic clinical networks, including Operational Delivery Networks (ODNs) became critical in supporting innovation and system wide collaboration. The proposed ICS reforms will support networks to drive clinically-led change and service improvement with greater accountability for tackling inequalities and for improving population health.

The North East and North Cumbria benefits from a single ICS which comprises of 4 Integrated Care Partnership areas;

- North Cumbria
- North of Tyne and Gateshead
- Durham, South Tyneside and Sunderland
- Tees Valley

The ICS is a commitment by all NHS organisations along with Local Authorities and other voluntary and third sector organisations, to work together on ambitious plans to improve the health of the three million people who live in the region and to improve the quality of their health and care services.



NENC ICS-wide

North East Ambulance Service FT covers: North of Tyne and Gateshead ICP; Durham, South Tyneside and Sunderland ICP; Tees Valley South ICP

CNTW Mental Health FT covers: North Cumbria ICP; North of Tyne and Gateshead ICP; plus part of South Tyneside and Sunderland ICP

TEWV Mental Health FT covers: Tees Valley ICP; plus part of South Tyneside and Sunderland ICP

Newcastle upon Tyne Hospital FT: provider of highly specialised and specialised national and regional services (including transplant, paediatric specialisms and major trauma)

North of Tyne and Gateshead ICP

Population: 1.079M
3 CCGs: Northumberland, North Tyneside, Newcastle Gateshead
Primary Care Networks: 24
3 FTs: Northumbria, Newcastle, Gateshead
4 Council Areas: Northumberland, North Tyneside, Newcastle, Gateshead

Durham, South Tyneside and Sunderland ICP

Population: 997,000
4 CCGs: South Tyneside, Sunderland, North Durham*, DDES*
Primary Care Networks: 24
2 FTs: South Tyneside & Sunderland, County Durham and Darlington
3 Council Areas: South Tyneside, Sunderland, County Durham
*County Durham CCG from 1st April 2020

Tees Valley ICP

Population: 852,000
4 CCGs: HAST*, Darlington*, South Tees*, HRW
Primary Care Networks: 17
3 FTs: County Durham and Darlington, North Tees & Hartlepool, South Tees
6 Council Areas: Hartlepool, Stockton on Tees, Darlington, Middlesbrough, Redcar & Cleveland, North Yorkshire
* Tees Valley CCG from 1st April 2020
Yorkshire Ambulance Service

North Cumbria ICP

Population: 324,000
1 CCG: North Cumbria
Primary Care Networks: 8
1 FT: North Cumbria Integrated Care NHS Foundation Trust (NCIC)
1 Council Area: Cumbria County Council (with 4 District Councils)
North West Ambulance Service

Providers in every system, through partnership or any new collaborative arrangements, must be able to agree proposals developed by clinical and operational networks, and implement resulting changes. These changes include implementing standard operating procedures to support agreed practice, designating services to ensure their sustainability or wider service reconfiguration.

Clinical networks at system, regional and national level have important roles advising on the most appropriate models and standards of care, in particular making decisions about clinical pathways and clinically-led service change.

What does this mean for our Network?

What this means in practical terms is still under review and we await further guidance to be published later this year on proposed changes to financial arrangements and accountability for the Network. The Network team have attended a number of meetings hosted by NHS England where they have discussed the need for networks to have greater responsibility and accountability. The Network team will update the board as information becomes available.

Research

The congenital heart disease (CHD) research group sits with the theme of Reproduction, Development and Child Health which cross-cuts the three core Institutes of the Faculty of Medical Sciences at Newcastle University

- Biosciences
- Translational and Clinical Research
- Population Health Sciences

This group leads CHD research across the North East and North Cumbria-CHD Network. Clinicians hold honorary contracts appropriate to their level of involvement.

Research Meetings

Meetings have almost exclusively been online this year in view of Covid 19. The group has held a successful seminar series with speakers ranging from students to international speakers covering basic science to applied health care research. Speakers have included Professor Kim Martinod, Professor Philip Moons, Professor Nigel Drury and Dr Laura Delaney.

Cardiac Morphology Meeting: A multidisciplinary meeting integrating basic science concepts and advances in anatomy and development with clinical imaging and intervention

Cardiac Development and Congenital Heart Disease Meeting Weekly Friday 1-2pm: Held each Friday in term time at the Institute of Genetic Medicine. Formal presentation of research, both clinical and laboratory based.

Business Research Meetings Friday 1-2pm 3 monthly: Updates on Restructuring, Funding and Other Initiatives relevant to group

Congenital Heart Disease Seminar Series Friday 1-2pm monthly

Clinical Journal Club Tuesday 8am

Research Support

Clinical Research Network North East and North Cumbria (https://www.nihr.ac.uk/nihr-in-your-area/north-east-and-north-cumbria/), 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.

- 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 Debbie McParlin in the delivery of the Approach II study (PI LC) and the Revival study (PI MN).

Research Themes and Current Projects

See appendices for a list of Publications.

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, Dr Louise Coats 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 I 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

- Do healthcare professionals working in a paediatric specialist cardiac centre understand the government's activity guidelines for children and infants? , Karen Caulfield, Louise Coats Niina Kolehmainen
- Understanding the experiences of children with mechanical support, Dr Emma Simpson, Dr Zdenka Reinhardt, Professor Judith Rankin
- 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
- Parent-led interventions to improve sleep for cardiac patients in the PICU and ward. Dr Emma Simpson, Professor Judith Rankin, paediatric cardiac multidisciplinary clinical team
- Early life factors in Multimorbidity Louise Coats, Simon Bamforth, Helen Philips, Judith Rankin, Mike Taggart, Niina Kohlehmainen
- Understanding inborn errors of metabolism in paediatric cardiomyopathy; Dr Helen Phillips and Dr Simon Bamforth.
- Artoria-R International Registry Louise Coats, David Crossland, Thibault Petit

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 Nassar (with Dr Lian Gan, Durham University)

ACHD

- Testing the Validity of ECG Parameters in Predicting Adverse Outcomes in Congenital Heart Disease, Dr Louise Coats, Dr Bill Chaudhry

- Understanding what matters to Adults with Congenital Heart Disease to develop Better Service Provision, Dr Louise Coats, Dr Bill Chaudhry
- Understanding what matters to those with Congenital Heart Disease across the lifecourse and those caring for them to develop Better Service Provision, Dr Louise Coats, Prof Judith Rankin, Kaye Walsh
- Non-invasive assessment of Pulmonary Hypertension Dr Louise Coats, Prof Guy Macgowan
- 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)
- Percutaneous VSD Closure, National Outcomes Study, Dr David Crossland

Funding

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**

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**

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, 2022-23, £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, Dr Louise Coats**

British Heart Foundation Project Grant (PG/20/15/35041), 2021-2024, £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**

Newcastle Hospitals Charity (NU-005457) "Identifying cellular heterogeneity underlying susceptibility to atherosclerosis", April 2021 – January 2023; £48,396. **Dr Simon Bamforth**

British Heart Foundation Non-Clinical PhD Studentship (FS/PhD/20/29032)
"Pax9 regulation of extracellular matrix production in the pharyngeal endoderm", April 2021 – April 2024; £109,229. **Dr Simon Bamforth**

Medical Research Council, 2018 - 2022, £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

Future research and funding

ARC-NENC Application Submitted (Outcome known November 2021) **Lead applicant CHUF with Dr Louise Coats**

Multi-centre RCT of SGLT2 inhibition for Adults with failing systemic RVs, (PI Gruschen Veldtman, Glasgow), **local PI Dr Louise Coats, submitted to NIHR for funding**

ESRC An ethnographical study of paediatric heart failure patients following them up from diagnosis through to transplant. **Dr Emma Simpson, Professor Judith Rankin**

Markers of Esteem

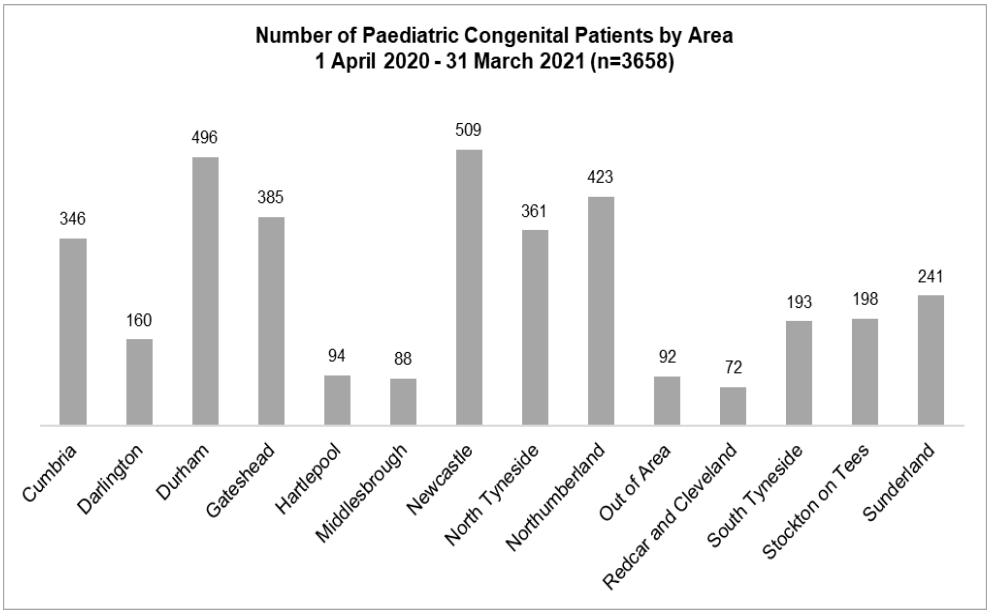
Dr Bill Chaudhry Chair of Nucleus in Working Group for Development Anatomy, and Pathology ESC.
Professor Deborah Henderson Former Chairperson of Nucleus in Working Group for Development Anatomy, and Pathology ESC.
Dr Louise Coats: National nominated reviewer for ESC ACHD Guidelines 2020, ACHD representative JLA Research Priority Setting Exercise 2021
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, Chair AEPC Heart Failure/Pulmonary Hypertension/Transplantation Working group 2021-2023, ISHLT Education Council Member Paediatric Heart Failure and Transplant, CTAG paediatric heart representative 2021-2023, BCCA Ordinary Council Member 2020-2022
Dr Abbas Khushnood, Clinical Domain Lead, NICOR
Dr Simon Bamforth, Editorial Board for the Journal of Cardiovascular Development and Disease

Our Network in Numbers

The 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 2020 and March 2021 as inpatients and outpatients.

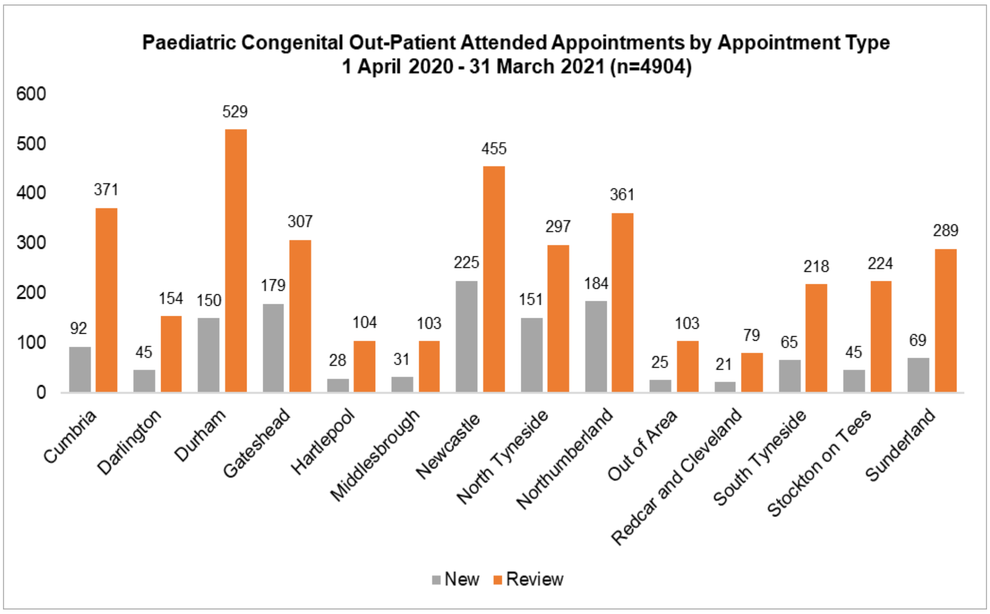
Paediatric Congenital Patients (April 2020 – March 2021)

The graph below shows the number of **paediatric patients** from across the region seen in the outpatient department at the Freeman Hospital. There were 3658 patients seen between April 2020 and March 2021, the largest number of paediatric CHD patients live in the Newcastle area (509) and the least number from Redcar & Cleveland (72).

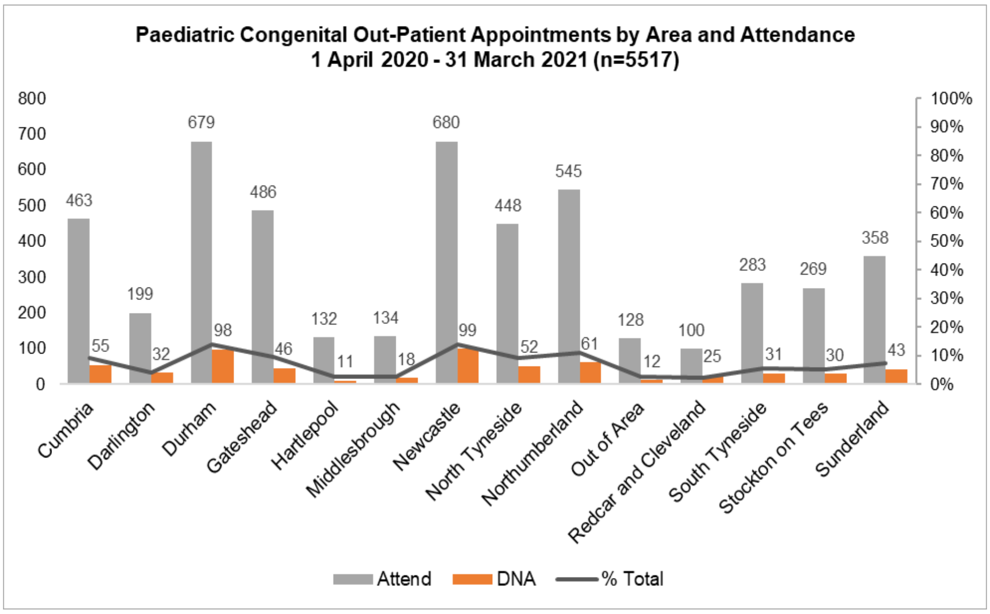


We would also like to represent CHD patients under the care of local teams and will be investigating how to collate this data during our peripheral centre visits to include in future reports.

The graph below shows the number of **appointments** for patients from across the region seen at the Freeman Hospital. Between 1 April 2020 and 31 March 2021 there were 4904 paediatric outpatient appointments, 1310 new and 3594 review[2].



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 total number of DNAs was 613 with the highest rate seen for patients from Newcastle (14%) and Durham (14%), the lowest were from the Hartlepool area (8%).



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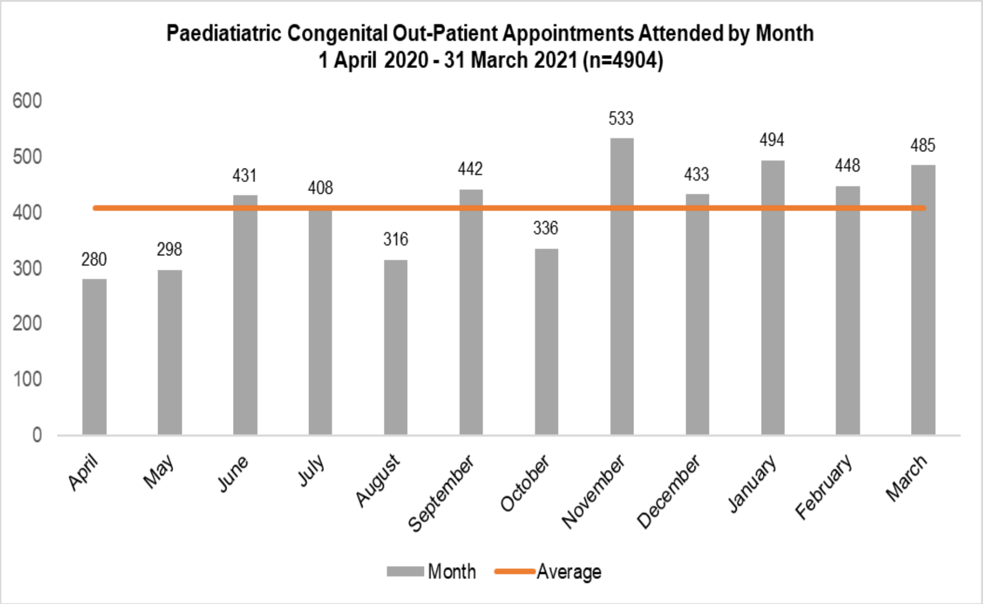
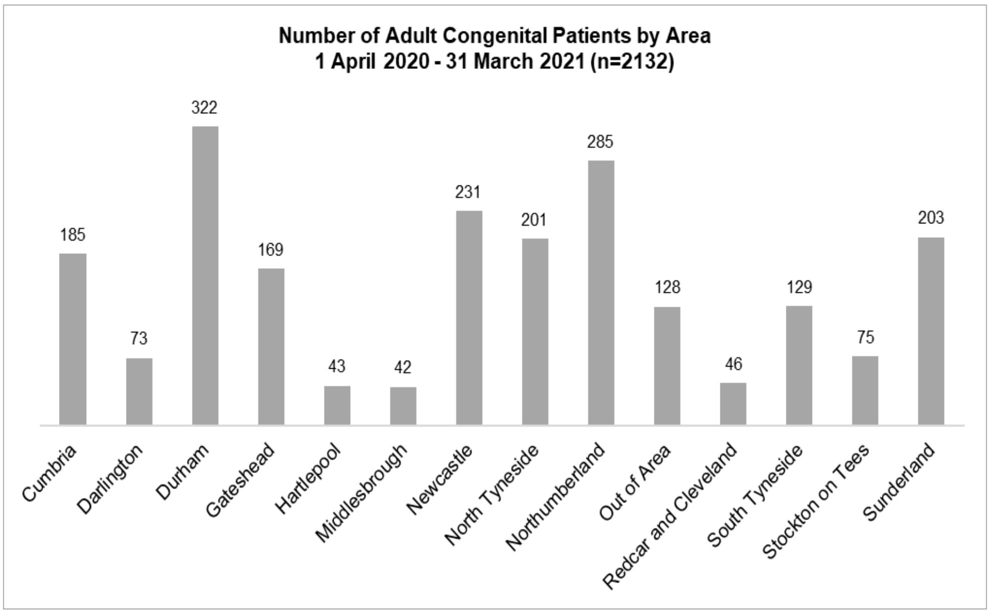
[2] Information generated by Information Services, NUTH.

On average 409 paediatric patients attended for outpatient appointments each month compared to an average of 485 per month over the last three years, a decrease of approximately 15.6%.



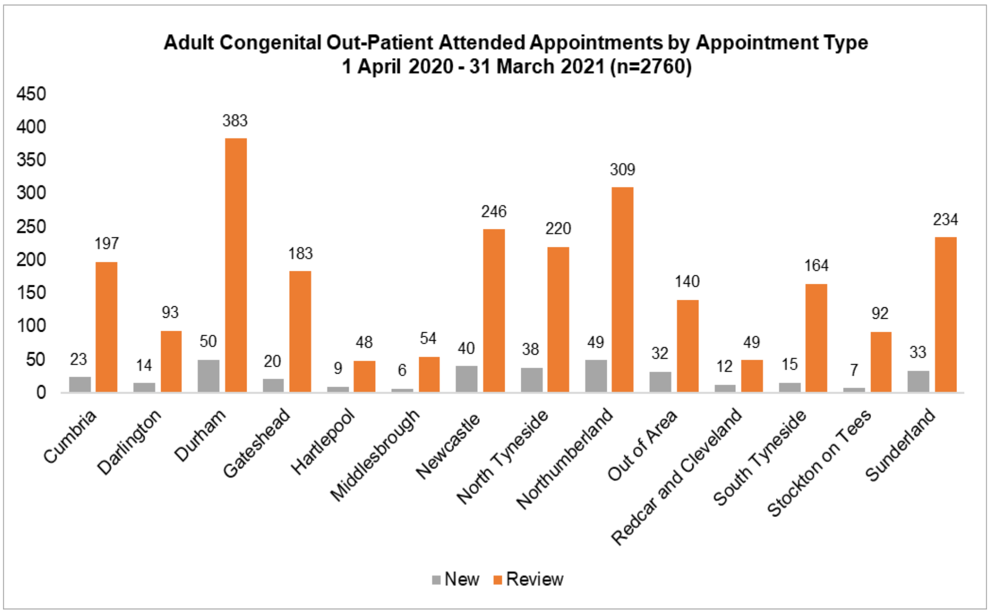
Adult Congenital Patients (April 2020 – March 2021)

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. There were 2132 patients seen between April 2020 and March 2021, the largest number of adult CHD patients live in the Durham area (322) and the least number from Middlesbrough (42).

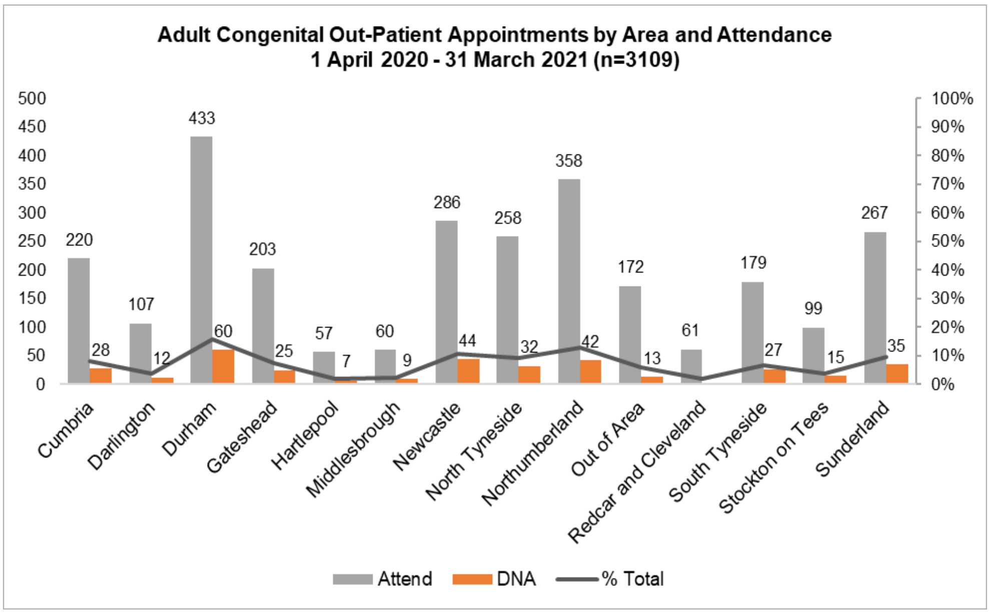


We would also like to represent CHD patients under the care of local teams and will be investigating how to collate this data during our peripheral centre visits to include in future reports.

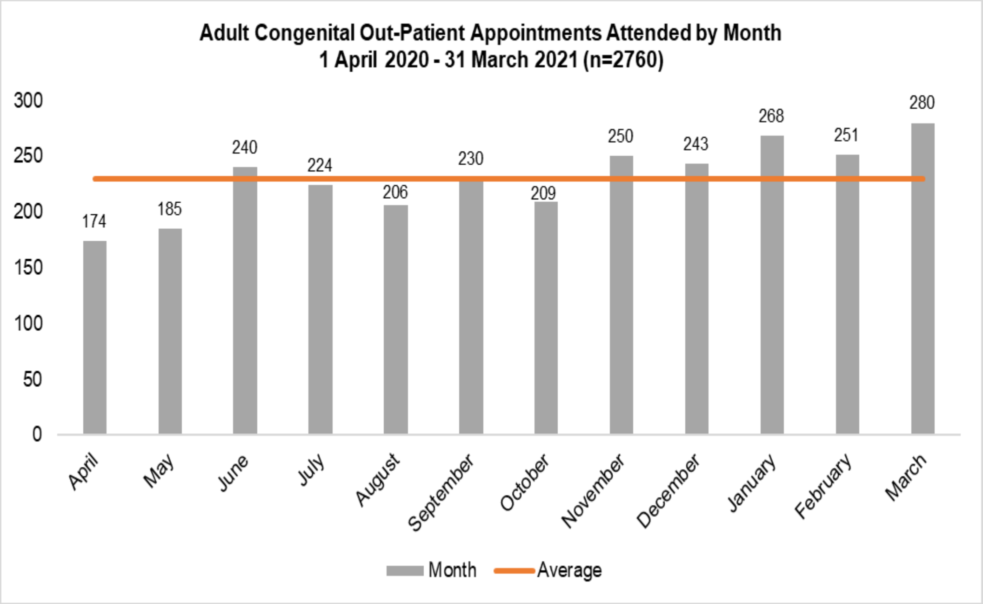
The graph below shows the number of **appointments** for patients from across the region seen at the Freeman Hospital. Between 1 April 2020 and 31 March 2021 there were 2760 adult outpatient appointments, 348 new and 2412 review.



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 Newcastle (15%) and Durham (14%) areas, the lowest from the Redcar and Cleveland area (0%).



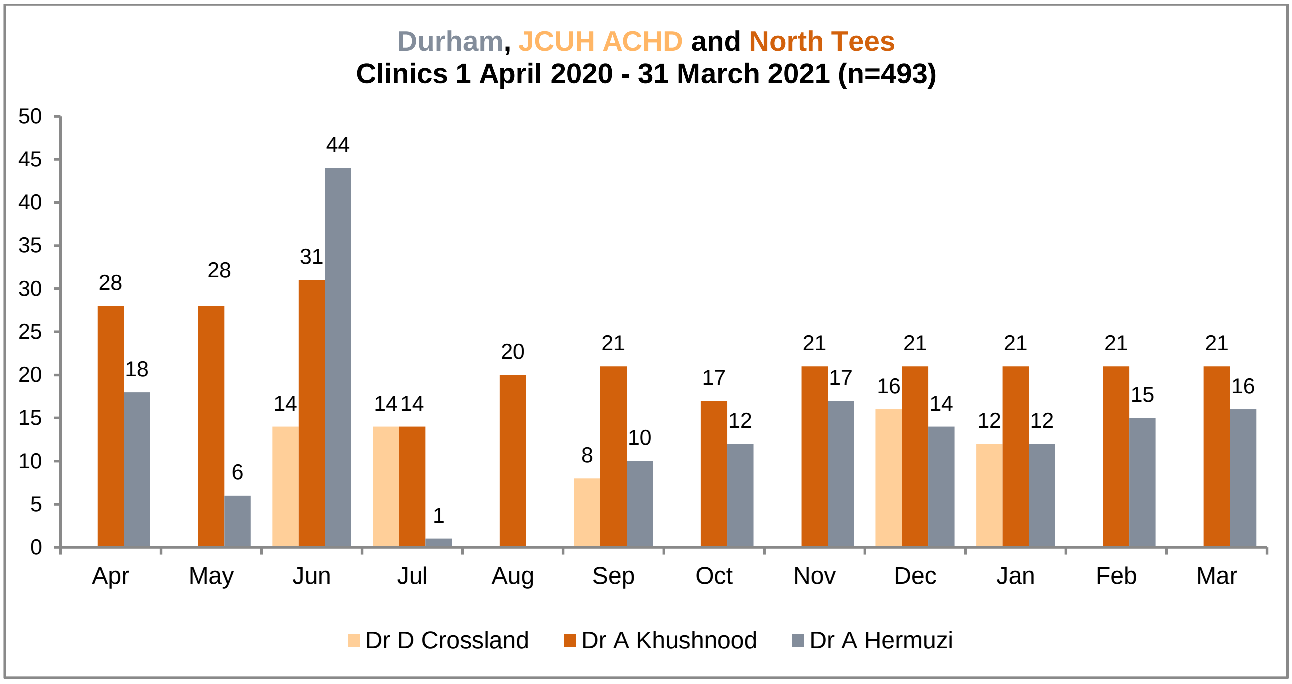
On average 230 per month compared to an average of 231 appointments each month for the previous 3 years, representing a slight decrease.



Outreach clinics (April 2020 – March 2021)

Although the pandemic had a significant effect on the provision of outreach clinics over the last year, many were able to go ahead, some virtually and some face-to-face with reduced patient lists due to covid restrictions.

Paediatric patients are seen at the Durham and North Tees clinics, and **adult patients** seen at James Cook University Hospital*.

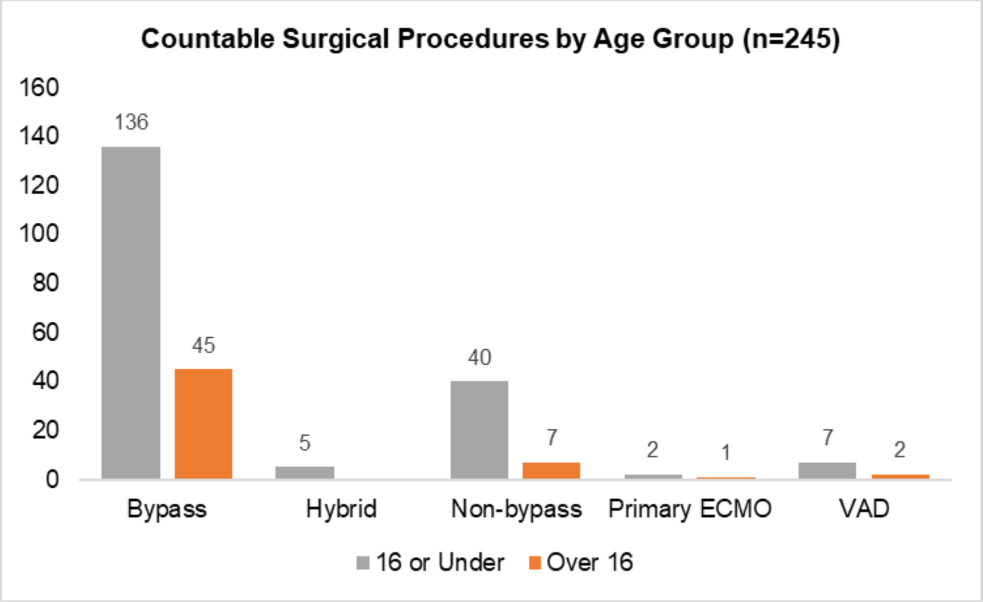


* Paediatric cases seen at JCUH were not available at the time of writing this report.

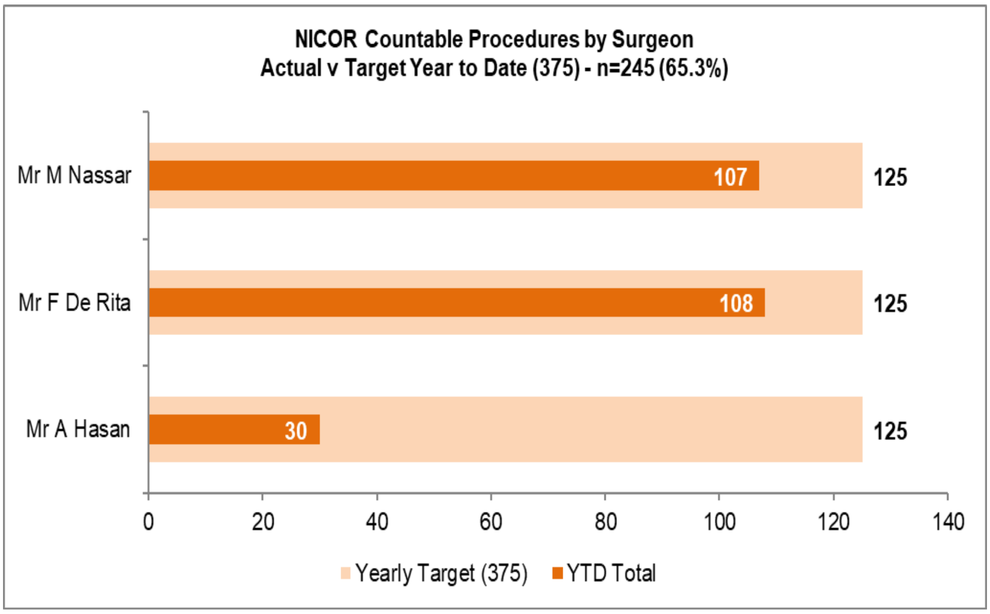
Inpatient Activity (April 2020 – March 2021)

Surgical Activity

The total number of countable surgical procedures carried out in the unit for 2020/21 was 245 which is 65.3% of the target of 375 procedures.

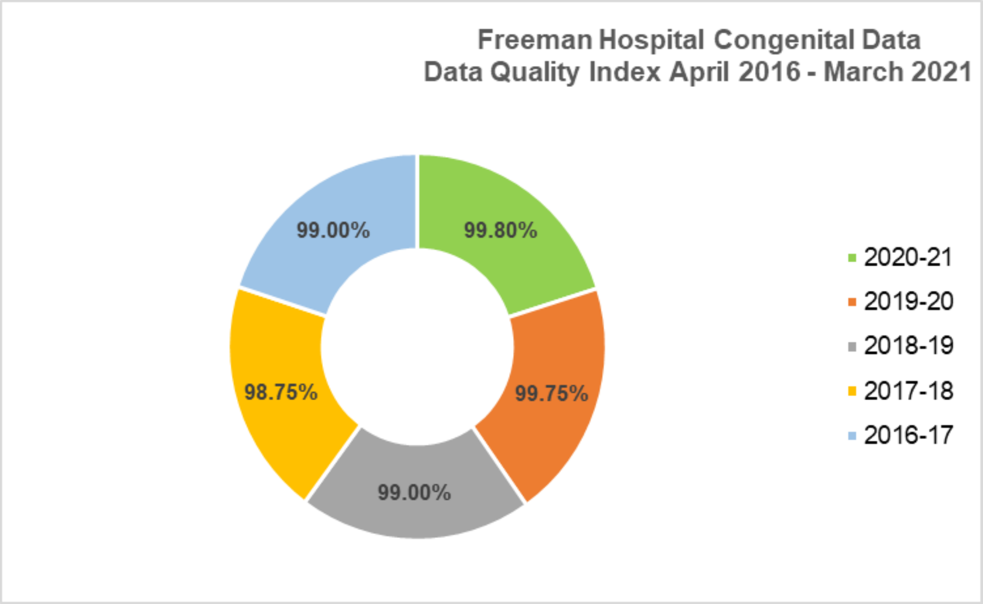


The target for each operator 125 procedures per year, the graph outlines the number of procedures carried out by each surgeon during 2020/21.



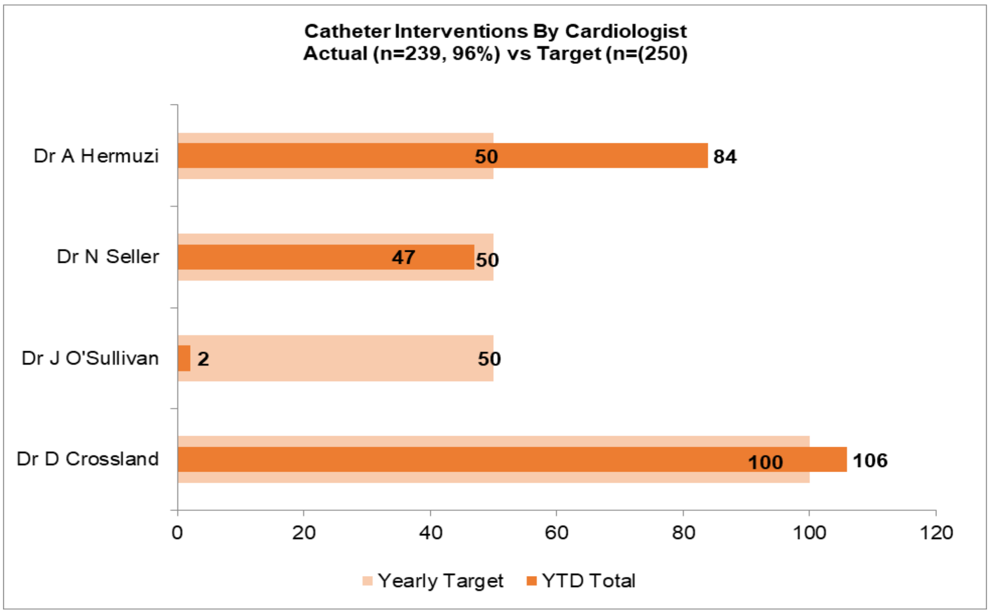
NICOR

The centre regularly submits data to NICOR (National Institute for Cardiovascular Outcomes Research) on surgical outcomes for CHD patients. The overall data quality index score (DQI) has been steadily increasing over the last few years, maintaining above 97%. The most recent DQI score for the Freeman Hospital for 2020/21 is recorded at 99.80%.

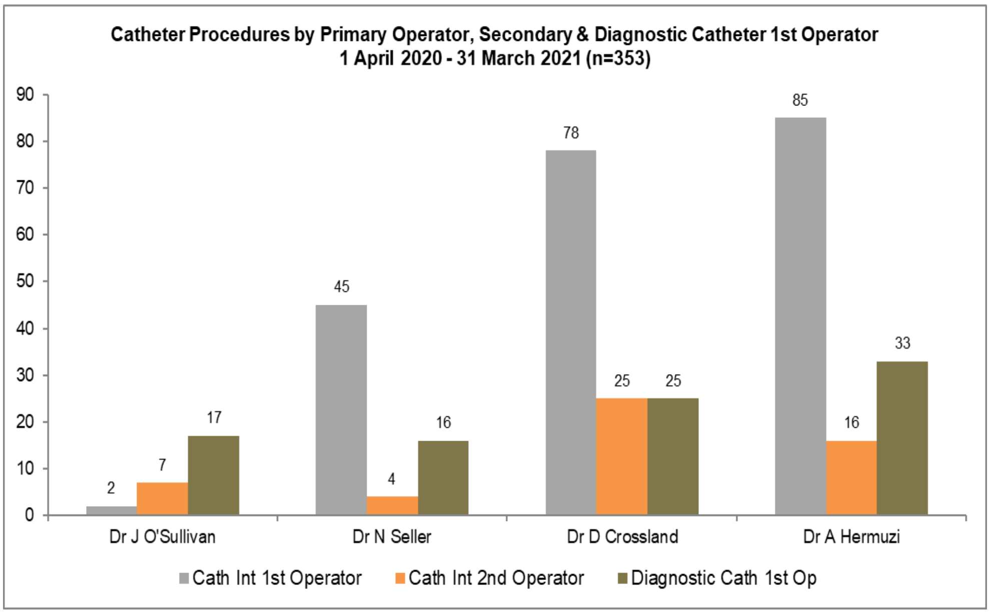


Cath lab procedures

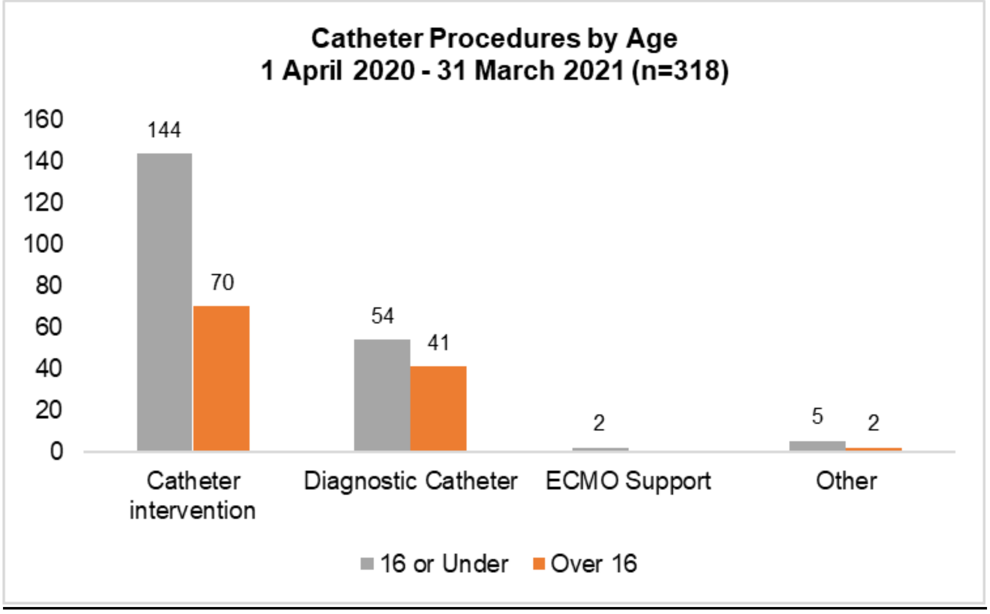
The total number of catheter interventions carried out in the unit for 2020/21 was 239 which is 96% of the target of 250 interventions.



The total number of interventions was lower in 2020/2021 (n=239) compared to 2019/2020 (n=318), a decrease of 25%. The number of interventions includes 210 carried out as a primary operator and 52 interventions carried out as second operator.

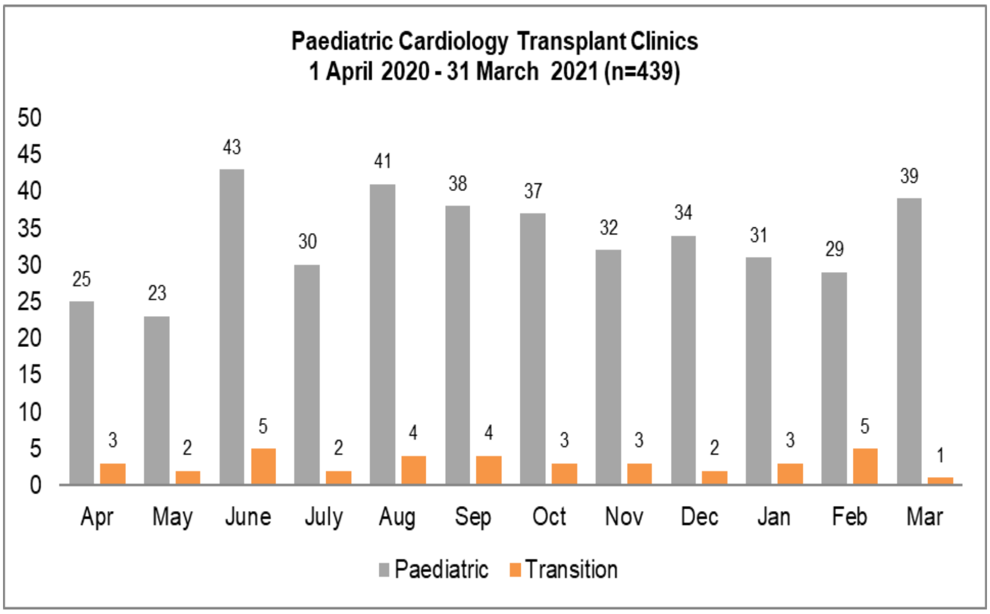


The graph below shows the number of catheter procedures by age group; similar numbers of catheter interventions were carried out in adults and children but more diagnostic catheter procedures carried out in children (54 cf. 41) which are expected.

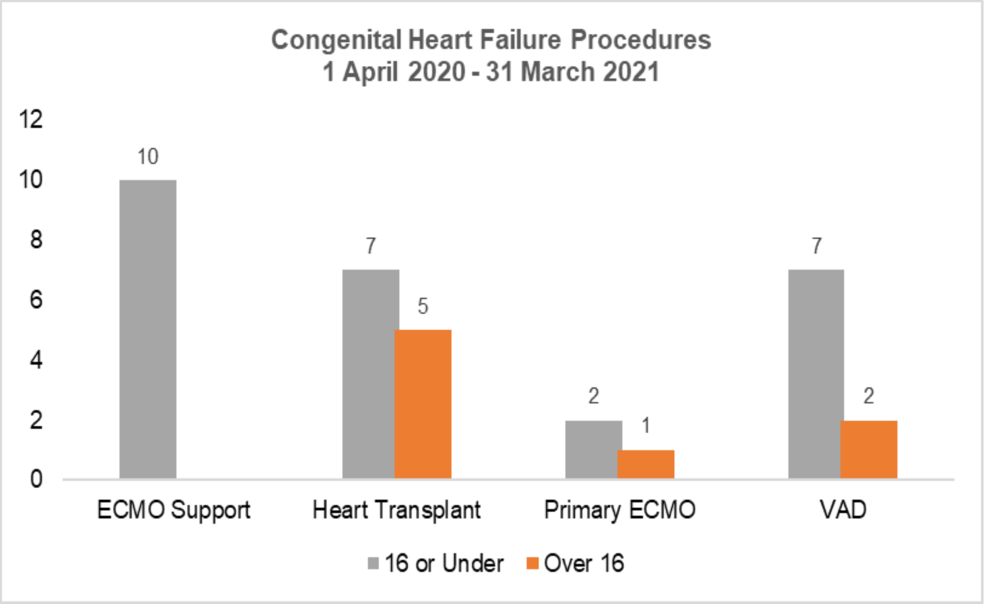


Transplant clinics

The graphs below show the number of transplant clinic appointments and assessments between April 2020 and March 2021, a total of 439 appointments. On average there were 34 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.



Appendices

Publications

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