



NORTH EAST AND NORTH CUMBRIA Congenital Heart Disease Network

Annual Report 2021/22

October 2022



Document History

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Foreword

This has been another challenging year as we come out of the acute COVID pandemic, move towards more normal working but with a backlog of cases and appointments to address. The fallout on the NHS from the pandemic will go on for some time and the recent financial crisis, following the terrible Ukrainian war and subsequent financial uncertainties, potentially makes future NHS funding even more fragile.

However, whilst the pandemic has, of course, had a major negative impact on the whole country it has accelerated some change which was needed. There are now few excuses for failing to engage with teaching and meetings when offered online via Teams. I would encourage as many as possible to grasp the opportunity to access training, teaching and to influence the future direction of the North east and North Cumbria Congenital Heart Disease Network. I would also encourage peripheral units to collect data on the congenital cardiac work done in order that we have a much more accurate view of patient activity and needs across the region.

Although Teams has been a boon, it was a joy to meet for a face to face Network Board meeting in October. This occurred at the Durham Centre and was, I think, one of the most useful meetings in the last two years. There was excellent input and ideas from a number of different services and areas in the network, with vital parent/patient views voiced. All who attended left enthused with wanting to improve the whole experience and journey for our patients. There will be task and finish groups established to assist the Network with developing our 3-5 year strategic plan and it is vital to have representation from across the region.

The Network is engaged with the Newcastle Hospitals NHS Foundation Trust as it negotiates and plans to bring Congenital Heart Services onto the Royal Victoria Infirmary site. Final plans and agreements have not yet signed off with NHSE.

My thanks go to the whole network team (listed below) and also the trustees, workers and supporters of the Children's Heart Unit Fund (CHUF) with whom we continue a close and fruitful relationship.

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 3.2 million¹ 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 Specifications² 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

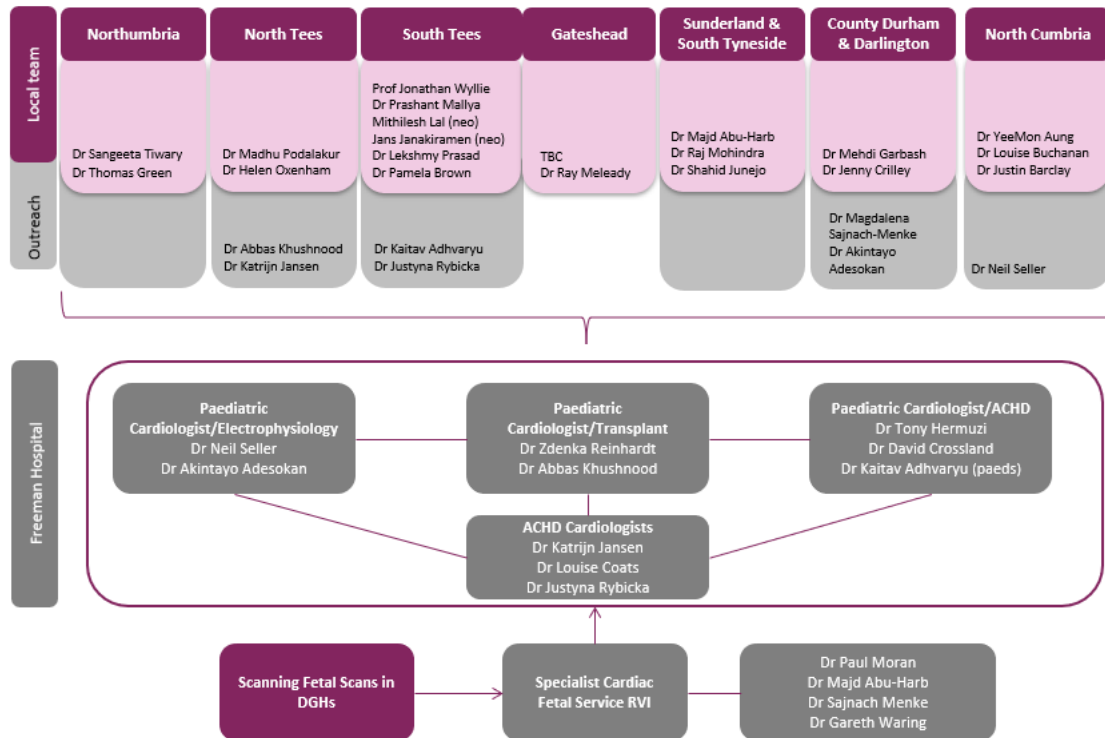
The network management team was formerly established in January 2020, comprising of the Network Chair (Jonathan Wyllie), Network Clinical Directors (Abbas Khushnood, Louise Coats), Network Manager (Terry Phillips), Network Lead Nurse (Kaye Walsh), data manager (Gwen Taylor) and Network Administrator (vacant position)

¹ <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates>

² <https://www.england.nhs.uk/wp-content/uploads/2018/08/Congenital-heart-disease-standards-and-specifications.pdf>

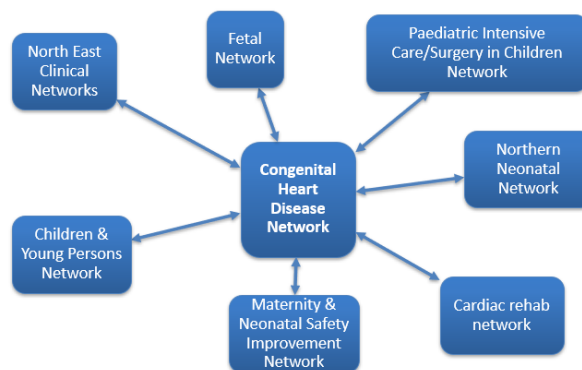
The key priorities and work of the network team is determined by the network board which is responsible for ensuring that the activities of the network staff are in line with agreed network priorities and are working towards the achievement of CHD standards.

Congenital Cardiac Service North East & North Cumbria



Network Relationships

Network Relationships



Network board meetings

The board meetings will continue with a blend of face-to-face meetings and virtual meetings via Teams. The time of the virtual board meetings will remain at 5pm to enable good attendance with one face-to-face board meeting per year held at 10am.

The board meeting dates for 2022/23 are listed below.

19/10/2022
01/02/2023
07/06/2023
08/11/2023

Board meeting attendance

Trust	Attendance	%
CDDFT	1	6%
Gateshead Healthcare	1	6%
Newcastle	15	83%
North Cumbria	3	17%
North Tees & Hartlepool	7	39%
Northumbria	2	11%
South Tees Hospitals	14	78%
South Tyneside & Sunderland	6	33%

Trust Updates

South Tees

Adult CHD Clinical Lead: Pamela Brown

Children's CHD Lead: Lekshmy Prasad

Neonatal CHD Lead: Prashant Mallya

Fetal CHD lead; Vedrana Caric

Key achievements, developments and highlights from 2021/22:

- Regular outreach clinics by Newcastle team.
- New ECG machine in COPD allowing ECGs to be done in clinic – Network provision
- Paediatric Cardiac Clinics run by 4 paediatric consultants

Consultant	Clinics	Patients Seen	
L Prasad	20	160	Only started Sep 2021
J Wyllie	72	576	Sick leave Jun/Jul/Aug
P Mallya	24	155	
S Janakiraman	?	?	
M Podulkar	2	16	Locum for JW S/L
M Lal	15	78	
Cardiogenetic Clinic	6	34 families	
Total	139	1019*	

6 Cardiogenetic Clinics run annually – Joint clinic seeing families with or at risk of inherited cardiac disease

Paediatric Cardiology Medical Student Selected Component established (4th Year)

Research projects completed/initiated in 2021/22:

Outcome of Neonatal and Infant Murmurs in the Modern Age (2019-2022) – Kaitlyn Smith, Jonathan Wyllie, Prashant Mallya

This was presented at the Network Board Meeting and is to be presented at the Neonatal Network Meeting.

Risks and challenges in 2021/22:

Lack of communication between both centres.

Patients potentially lost to follow up.

Growing number of patients without dedicated consultant time

Loss of the Teesside Psychology support for cardiac patients and their families

Ageing Echocardiogram Machines

Case Study

Patient referred into JCUH neonatal unit for respiratory failure at term ventilated. Brought by the Neonatal Transport Team on nitric oxide (NO). Relatively poor response to NO but improved sufficiently on NO plus inotropic support that ECMO was not appropriate. Neonatal team realised that the patient had stabilised on treatment but had then not improved further.

Requested and out of hours Paediatric Cardiology Review. Echocardiogram revealed Total anomalous pulmonary venous connection (TAPVC). Thought by the local team to be probably partial superior and partially inferior. Discussed with consultant at regional centre. Weaned off NO without any issue. Accepted for transfer to regional centre who identified inferior TAPVC with connection to the hepatic portal vein. Operated upon to correct the abnormality. Discharged back to shared care.

Could supply an anonymised picture if wanted

Northumbria-Healthcare Trust

Adult CHD Clinical Lead: Thomas Green

Key achievements, developments and highlights from 2021/22:

Set up of the network with improved integration between trusts and specialist services

Research projects completed/initiated in 2021/22:

N/A

Risks and challenges in 2021/22:

Momentum stalling

North Tees and Hartlepool

Adult CHD Clinical Lead: Helen Oxenham

Key achievements, developments and highlights from 2021/22:

Established a combined adult congenital heart disease clinic running every 7 weeks – at NTUH

Research projects completed/initiated in 2021/22:

N/A

Risks and challenges in 2021/22:

Echo provision for the ACHD clinic / communication between ACHD and NTUH/UHH teams

Patient and Family Engagement

The network team held a number of events where patients with CHD and families were invited to take part in an activity and share their experiences of living with CHD.

Graffiti workshop – Young Persons Group



Mum's wreath making workshop



Dad's golf event



Education and Training

The education and training programme continued this year with more training being delivered by Kaye Walsh face-to-face.

Cardiac physiology services – an introduction to cardiac physiology. This engagement webinar provided an insight into the services delivered at the Freeman Hospital. The sessions explored the technical aspects and challenges of congenital heart ECHO, included an interesting paediatric electrophysiology case and facilitated discussions around professional development options.

Practical paediatric cardiology, facilitated by Dr Abbas Khushnood the session covered two case discussions providing guidance on when to suspect CHD.

Nurses, ODPs and AHPs – the first was an introductory session which described a range of common congenital heart lesions and the issues that they may cause in children and adults. The second session focussed on recognition and stabilisation of the patient presenting with heart problems.

Trainees webinar covered case studies and practical approaches to managing the unwell presenting child. Topics included cardiomyopathy (presentation and initial management) and vulnerable baby with shunt (BT/Sano/PDA stent) presenting acutely unwell to a DGH.

St Oswalds bespoke study days held at St Oswalds in Newcastle which described a range of common congenital heart lesions and the issues that they may cause in children and adults.

County Durham and Darlington bespoke trainee nurse practitioners' education session – a detailed education session providing the team with specific knowledge in recognition and management of the sick child with CHD.

Adult rehab team Northumberland – morning session planned for September to educate and empower the team in common ACHD conditions with the aim to enhance the pathway of care for patients living with ACHD and their access to rehabilitation programmes in the community.

Clinical Educator

The Network are using the non-recurrent funding to support a paediatric clinical educator secondment role on ward 23 at the Freeman Hospital for 12 months to deliver standardised training and competency-based education.

Elaine Telford is an experienced paediatric cardiology nurse with an interest in developing others through education and support across the region. Elaine will share her knowledge and experience to support regional paediatric teams and enhance their cardiology skills.

Service development and ongoing/future projects

NHSEI non-recurrent funding

In November 2021 the Network was awarded non-recurrent funding from NHS England & Improvement via Specialised Commissioning to the value of £220,500. The Network team had applied for the funding in order to progress with a number of projects and the funding was primarily to provide salaries and posts in support of these.

Below is an outline of where the funding has been spent and the centres that have benefitted. The Network team were keen to ensure that all Trusts had an opportunity to benefit from this funding.

Further details of some of these initiatives are described later in this section.

Category	Examples	Cost	Centres
Patient and Family engagement		£ 26,613.92	
Education	Cardiology conference FINE course ECHO course	£ 9,809.00	
Equipment	Psychology tools BP monitors ECG monitors ECG machines Stethoscopes Laptops Webcams	£ 78,973.65	NCIC STSFT CDDFT STEES NUTH
Workforce & outreach	Carlisle paediatric outreach clinic Durham paediatric outreach clinic Stockton ACHD outreach clinic Nutrition clinic Network nurse educator Clinical psychologist	£ 105,029.00	NCIC CDDFT NUTH NTEES Network
Total spend		£ 220,425.57	
Award value		£ 220,500.00	
Surplus		£ 74.43	

Honorary contracts

Applications have been made for clinicians in peripheral centres to carry out clinic sessions at the Freeman Hospital. If you are interested please contact Terry Phillips (terry.phillips1@nhs.net).

South ICP Paediatric Cardiology Service

There have been a number of meetings to discuss the development of a paediatric cardiology service in the South ICP, including Darlington, Stockton and Middlesbrough. The clinical teams have proposed a service outline and the next steps are to discuss the practicalities with the business managers from each service and outline a workplan with the view to write a business case for submission to NHSEI. Project progress will be updated at the quarterly board meetings.

Nutrition Clinic

The network is currently funding extra dietetic time for a weekly nutrition clinic for paediatric cardiology patients needing nutritional support. The nutrition clinic is Paediatric Dietitian and Specialist Nutrition nurse led and is based a Freeman outpatient department. The clinic appointments are face to face or over the phone.

The nutrition clinics enable us to monitor these children's nutrition when they are home/ in the community and intervene in a timely manner to allow both optimal nutritional care at home as well as early intervention of a deteriorating patient.

Suboptimal nutrition in this group is associated with poor growth and poor brain development. It can affect post-operative outcome; increase in length of hospital stay, longer periods of ventilation and increased risk of developing a hospital acquired infection and mortality.

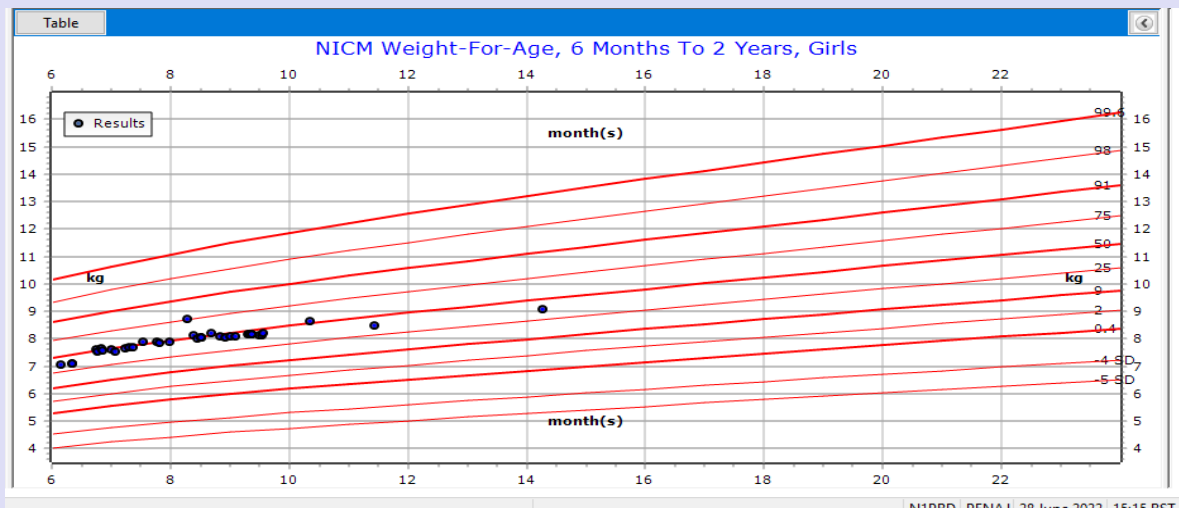
Case studies

Case study 1: LM:

Child with a very complex cardiac lesion who was receiving nasogastric tube feeds at home and waiting for a surgical procedure. The child was becoming more cyanosed and symptomatic at home. This included poor feed tolerance.

The child's admission for surgery was delayed several times due to bed and staffing pressures, as her condition deteriorated and her symptoms increased; cyanosis, shortness of breath, her feed tolerance was impaired, as a consequence her feeding plan had to be regularly adapted and monitored in order to minimise any nutritional deficits and maintain growth.

We managed to maintain her growth following regular input via the nutrition clinic, and at the time of the surgery, she was optimised nutritionally without any significant weight loss, see growth chart below (maintained her weight at 50th centile).



Case study 2: MR

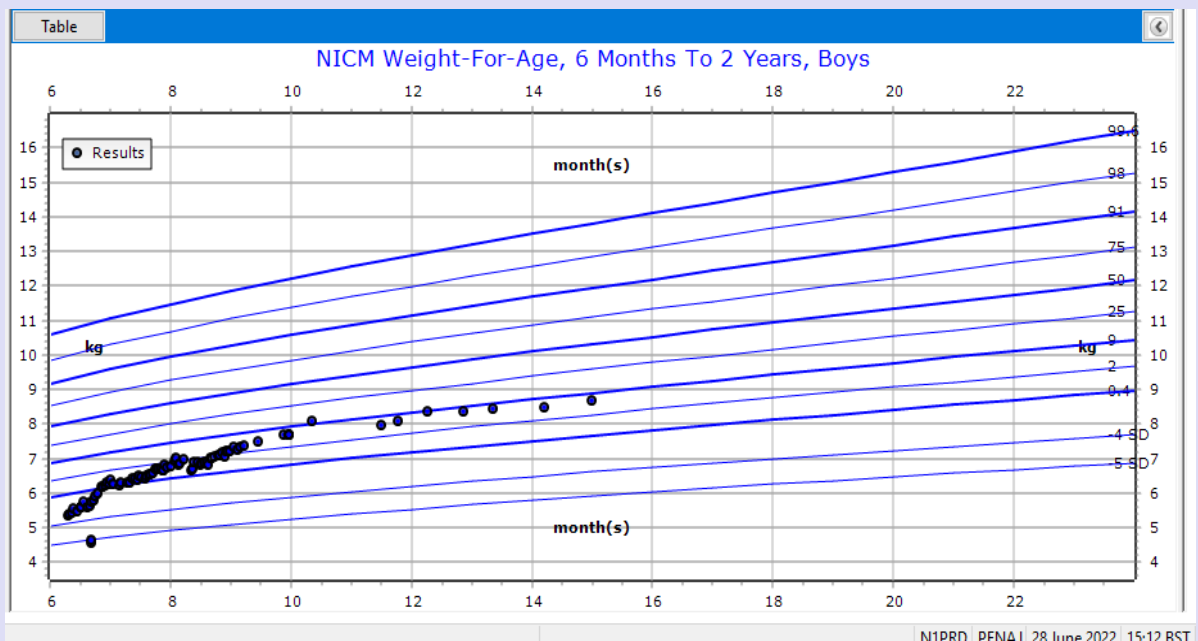
Child with complex cardiac lesion who was being treated for ongoing heart failure and poor cardiac function. The patient had been discharged home on full heart failure treatment, however remained fragile and in need of a significant amount of catch up growth, requiring nasogastric tube feeding. The patient had regular face to face follow up in the nutrition clinic and on one clinic visit was found to be very unwell with signs of deteriorating heart failure including severe subcostal recession, head bobbing, poor feed tolerance, pale and lethargic.

We alerted the consultant cardiologist to this, who then reviewed the child immediately in clinic and an urgent admission from the clinic was expedited.

The clinic enabled us to pick up early signs of deterioration in the clinical condition as the cardiology appointment had not been scheduled for some weeks later.

Following his admission the child was commenced on inotrope support and further medical intervention was given.

Following eventual discharge we continued to provide follow up support in the nutrition clinic and the child has now progressed to full oral diet without the need for the nasogastric tube.



Statements of support:

From Paediatric consultant cardiologist- Dr Abbas Khushnood

“Children with congenital heart disease (CHD) are prone to nutritional challenges and undernutrition. Growth and development is often compromised not only during unrepaired CHD and perioperative period but also during postoperative care. The calorie imbalance stemming from increased energy requirement from the heart and poor nutritional intake resulting from feed intolerance, fluid restriction or absorption issues can cause significant undernutrition. This can further precipitate frequent infections, delayed or poor wound healing and increased morbidity. Furthermore specific nutritional approach may also be required in patients with complications like chylothorax or protein-losing enteropathy.

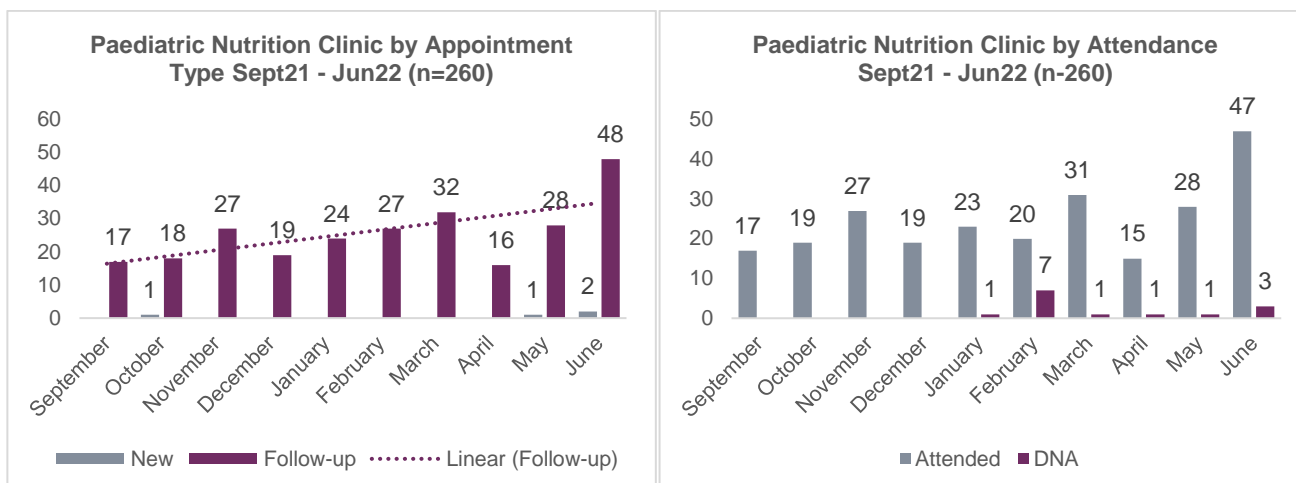
Therefore, nutritional treatment is vital in all paediatric patients with congenital heart disease and should be considered comparable to medical therapy. The setup of Nutritional Clinic has been a milestone development within our Network service. It has been able to provide excellent continuity of care both while patients are in-hospital and discharged home. As cardiologists, we have seen a huge improvement in overall nourishment, growth and development in our patients with significant heart lesions”

From children’s cardiac nurse specialist team:

“Babies and children with specific heart conditions often require additional calories to maintain and gain weight. The commencement of the nutrition clinic has enabled the team to keep a closer eye on the babies and children who are growth faltering or need additional support in their diet requirements. The nutrition clinic is a safety net for babies whose weight gain is slow or static and otherwise ready for home, this provides reassurances to the team that the babies will be monitored more closely and can promote early discharge. Having the specialist cardiac nurse and dietician work as a team to ensure the babies are receiving optimal nutrition to allow growth at home preventing hospital admissions. Using their expert experience the team work collaboratively often thinking out of the box to achieve this. Due to the large geographical cardiac network, we rely on local community dietician support to advise families, however, these teams don’t necessarily have the expertise to manage the more complex babies which means the nutrition clinic based at the Freeman provides a unique approach and valuable service. In addition to this it has eased the workload of the cardiac nurse specialists by having an established nutrition service and working collaboratively. It would be a great loss to the Northeast and North Cumbria Congenital Heart Disease Network and families if this clinic was not to be funded indefinitely”

From parent of a cardiac child attending clinic:

“My son Ethan uses the nutrition clinic on a weekly or bi weekly basis as he struggles to gain weight mainly due to a cardiac condition. We have spent a lot of time in hospital where we saw a dietician almost every week we could change and react to his challenging needs. The nutrition clinic run that on a Monday afternoon has provided me with a great comfort knowing that support is available every week or should things be going well biweekly or monthly, now we are out of hospital. The clinic allows us to be fairly reactive, a weekly weigh in means we can track Ethan’s progress and discuss and make changes, to type of milk, quantity or concentration of feeds. I can take the opportunity to talk through his feeding behaviours and get advice. The clinic offers almost real time advice on reducing weight loss, avoiding dehydration and understand and potential knock on consequences. The fact this clinic exists means I don’t have to wait potentially months to see a dietician in their normal outpatients calendar and the ability to just check in makes me feel reassured that I am supported in such a difficult situation. The clinic also links into advice from paediatricians that have suggested a surgical intervention, to try and help which I may have only got through an inpatient admission due to an issue otherwise. It is an amazing and treasured step in between inpatient and “normal” outpatient care. Thanks Gemma”



Aortopathy Service

Initial discussions have taken place led by Nic Child from North Tees & Hartlepool NHS Foundation Trust to outline a proposal for developing a aortopathy service across the North East and North Cumbria. The project is still at the service requirements gathering stage and progress will be updated at the quarterly board meetings.

CHD Database

The Data Protection Impact Assessment is in the final stages, a standard operating procedure (SOP) and data template have been drafted. The Terms of Reference for the Network board members has been reviewed to include a data processing agreement. This will enable teams across the region to submit clinic data in order for the Network to have a better understanding of the number, location and complexity of CHD patients in our region.

The Network have successfully submitted an NCARDRS data request application and are awaiting the first submission of data which will include historical data submitted to NCARDRS dating back to 1984.

All data, either submitted by regional Trusts or NCARDRS, will be held in an Access database on NuTH network and will only be accessible by the Network Manager and CHD Data Analyst. Requests for aggregate data can be made to the Network Manager as per the SOP.

eRecord development

The Network team have been working with the NuTH information team on an eRecord development project to help identify CHD patients and address patients being lost to follow up.

ACHD workforce

The Network team have been working with the NHSEI national team on a demand and capacity project. The project is comparing the number of adults with CHD in each regional population with the number of WTE cardiologist with specialist training in CHD and the number of ACHD nurse specialists. These figures are compared with the minimum requirements as outlined in the NHSE CHD National Specifications³ to estimate the current and future shortfall in workforce capacity.

³ <https://www.england.nhs.uk/wp-content/uploads/2018/08/Congenital-heart-disease-standards-and-specifications.pdf>

Current figures for the North East and North Cumbria show a shortfall of 6.6WTE ACHD cardiologists based on current population of 3.2 million⁴. Based on this population figure, the current ACHD population is estimated to be 13,686 (based on a prevalence of 4 per 1000 adults⁵). However, it has been suggested that this prevalence figure is significantly less than experienced.

Cardiac rehab

The Network team have been working with the cardiac clinical network on improving access to cardiac rehabilitation for adults with CHD. Face-to-face and webinar training has been arranged with location centres and a half-day training event is planned for January 2023.

vCreate

After a number of setbacks, we are hoping this project will start in autumn 2022. The vCreate platform will support post-surgery reviews and vulnerable babies and will be trialled in James Cook Hospital (Middlesbrough), University Hospital of North Tees (Stockton) and Cumberland Infirmary (Carlisle).

Postnatal diagnosis review

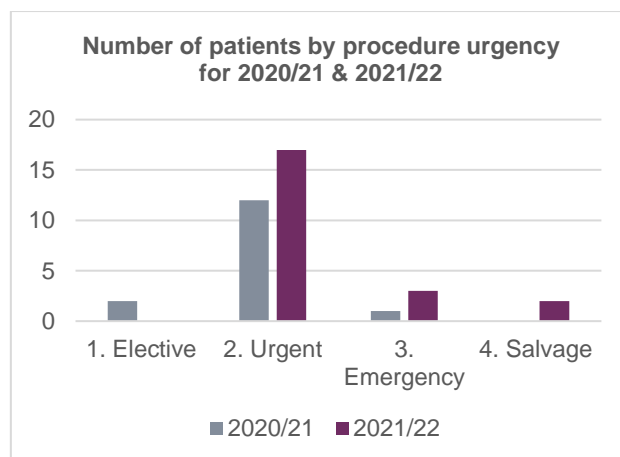
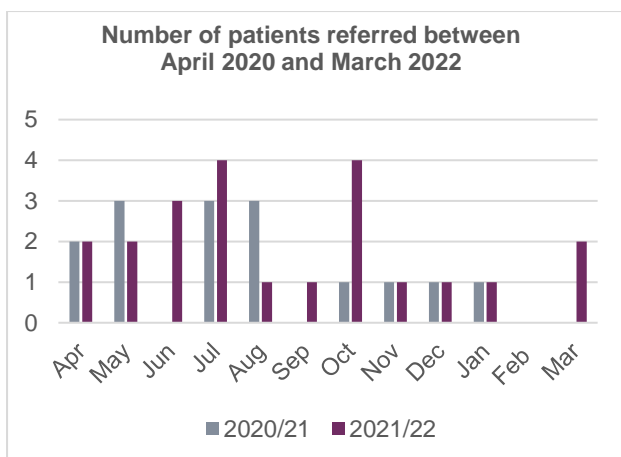
We have started a project working with the maternity and fetal medicine teams in the region to review postnatal diagnosis of CHD. We reviewed the data between January 2020 and April 2022 and included postcode analysis. During this time period there were 41 infants diagnosed postnatally with congenital heart disease. The table below shows the number by postcode area;

AREA	NUMBER OF PATIENTS
COUNTY DURHAM	9
SOUTH TYNESIDE	5
SUNDERLAND	2
GATESHEAD	1
NEWCASTLE	2
NORTH TYNESIDE	2
NORTHUMBERLAND	3
NORTH CUMBRIA	5
HARTLEPOOL	1
MIDDLESBROUGH	5
REDCAR & CLEVELAND	1
STOCKTON ON TEES	5
TOTAL	41

Some initial findings are outlined below and the Network team will feedback at quarterly board meetings.

⁴ <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates>

⁵ <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e05/>



The top 10 diagnoses are listed below.

DIAGNOSIS	NUMBER OF PATIENTS
092721. PATENT ARTERIAL DUCT (PDA)	37
010400. CONCORDANT ATRIOVENTRICULAR CONNECTIONS	27
092822. LEFT AORTIC ARCH	24
010500. CONCORDANT VA CONNECTIONS	21
072100. INTACT VENTRICULAR SEPTUM	13
050402. ASD WITHIN OVAL FOSSA (SECUNDUM)	12
050301. PATENT FORAMEN OVALE (PFO)	11
050401. INTERATRIAL COMMUNICATION ('ASD')	11
092901. AORTIC COARCTATION	7
060191. TRICUSPID REGURGITATION	7

Mental Health Review

The Network are using the non-recurrent funding to support two clinical psychologists (total 0.5WTE) to provide 1:1 psychology sessions for ACHD patients and carry out a mapping exercise for the ACHD patients and staff teams.

We are in the process of outlining the 6 month project with defined objectives based on some initial patient and family feedback and the NHSE CHD National standards. The aim of the project is to redesign the current mental health service offered to both patients and families in the region and formulate a business case to submit to NHSEI on behalf of the region.

In addition, we are reviewing the support provided to children and families across the region with the aim to redefine the service offer. This service is supported by CHUF and their funding has been ring-fenced until the new service has been defined.

Other Projects

JLA priority setting partnership for research in CHD

Louise Coats sat on the steering committee, Kaye Walsh and Katrijn Jansen attended workshops. Louise will present this at the BCCA conference in November 2022.

<https://www.birmingham.ac.uk/research/cardiovascular-sciences/research/congenital-heart-disease-priority-setting-partnership.aspx>

E learning for healthcare

We were delighted to be contributors to the development and launch of the ELHP online congenital heart disease modules. The collaborative national CHD project successfully delivered three online modules to enhance CHD education provision.
<https://www.e-lfh.org.uk/programmes/congenital-heart-disease/>

Approach IS II International Study

Louise Coats and Deb McParlin have successfully recruited more than 200 patients to the Approach IS II study which is looking in to patient-reported outcomes and experiences in adults with congenital heart disease.

So far, 53 centres in 32 countries have confirmed participation in the study. All centres have started recruitment and data collection, currently there are 8167 patients included in PART 1 of APPROACH-IS II and 858 patients included in PART 2 of APPROACH-IS II.
<http://www.approach-is.net/>

Next year

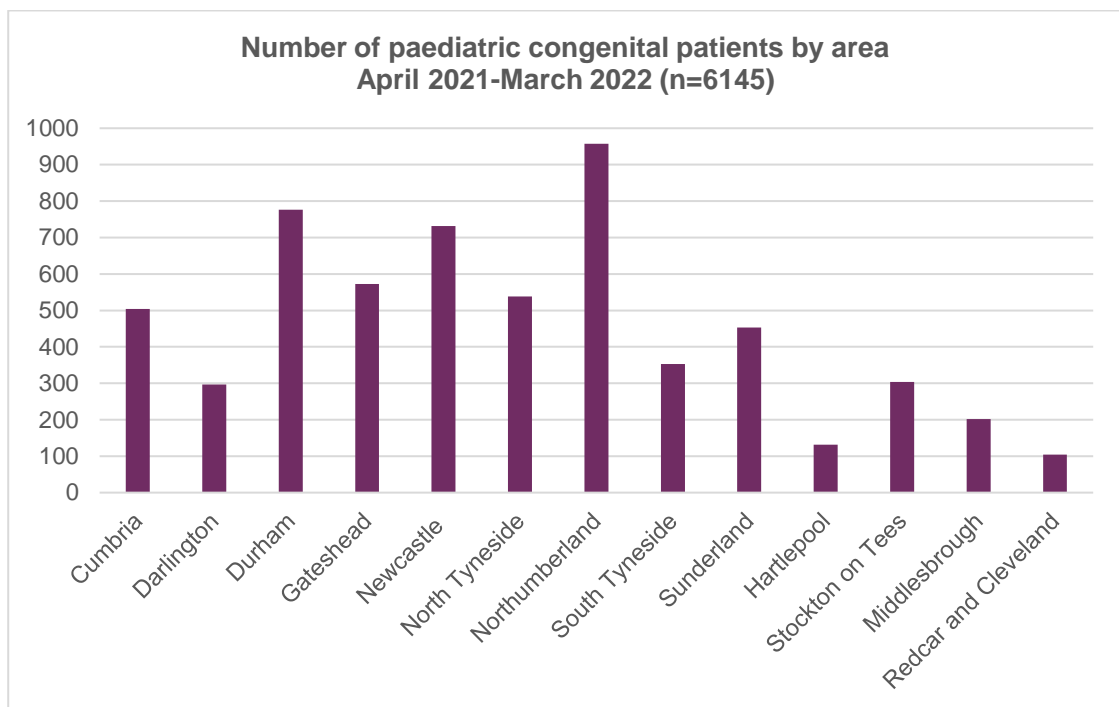
The Somerville Foundation will be holding their patient conference in Newcastle on 13th May 2023 at the Inside by Melia on Newcastle Quayside. The Network team will be supporting the Foundation in delivering this conference which will focus on 'Living Well with CHD'. A number of presentations are planned throughout the day as well as wellbeing workshops and activities which will run alongside.

Our Network in Numbers

The network covers a population of 3.2 million people across a wide geographical area. The information below describes the distribution of the patients who have attended the Freeman Hospital between April 2021 and March 2022 as inpatients and outpatients.

Paediatric Congenital Patients (April 2021 – March 2022)

The graph below shows the number of paediatric patients from across the region seen in the outpatient department at the Freeman Hospital. There were 6145 appointments between April 2021 and March 2022, the largest number of paediatric patients live in the Northumberland area (957) and the least number from Redcar & Cleveland (104).

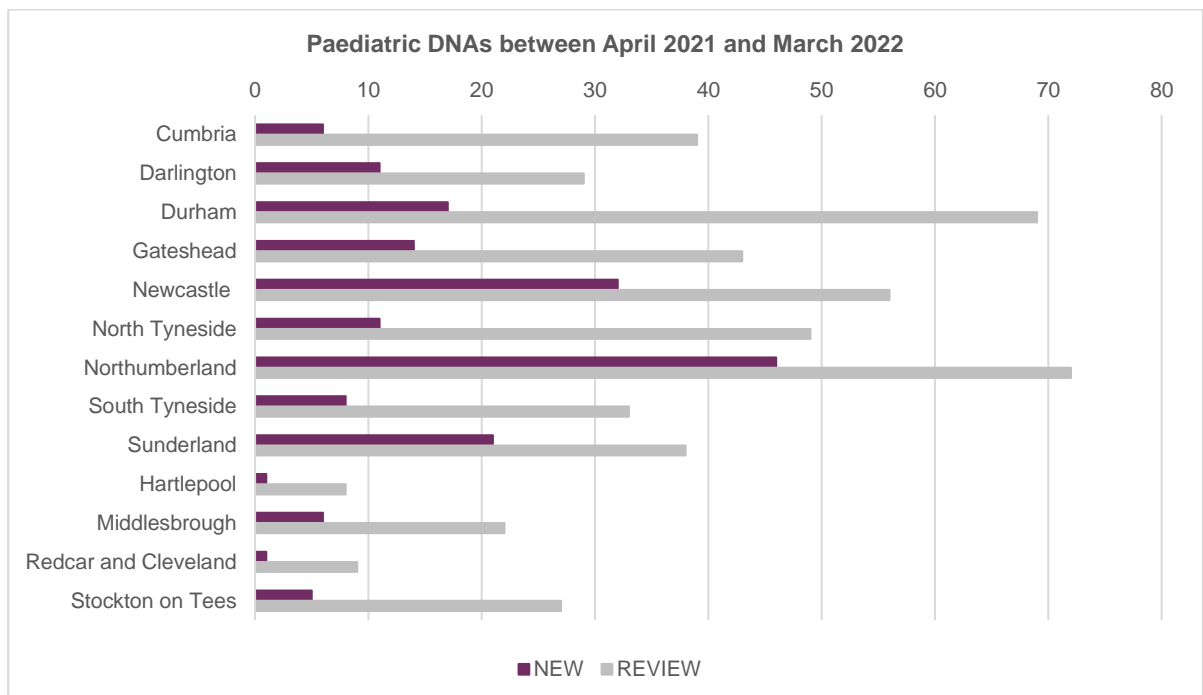


We would also like to represent CHD patients under the care of local teams and will be investigating how to collate this data during our peripheral centre visits to include in future reports.

The graph below shows the number of appointments for patients from across the region seen at the Freeman Hospital. Between 1 April 2021 and 31 March 2022 there were 1520 new appointments, 3927 review appointments and 673 DNAs⁶.

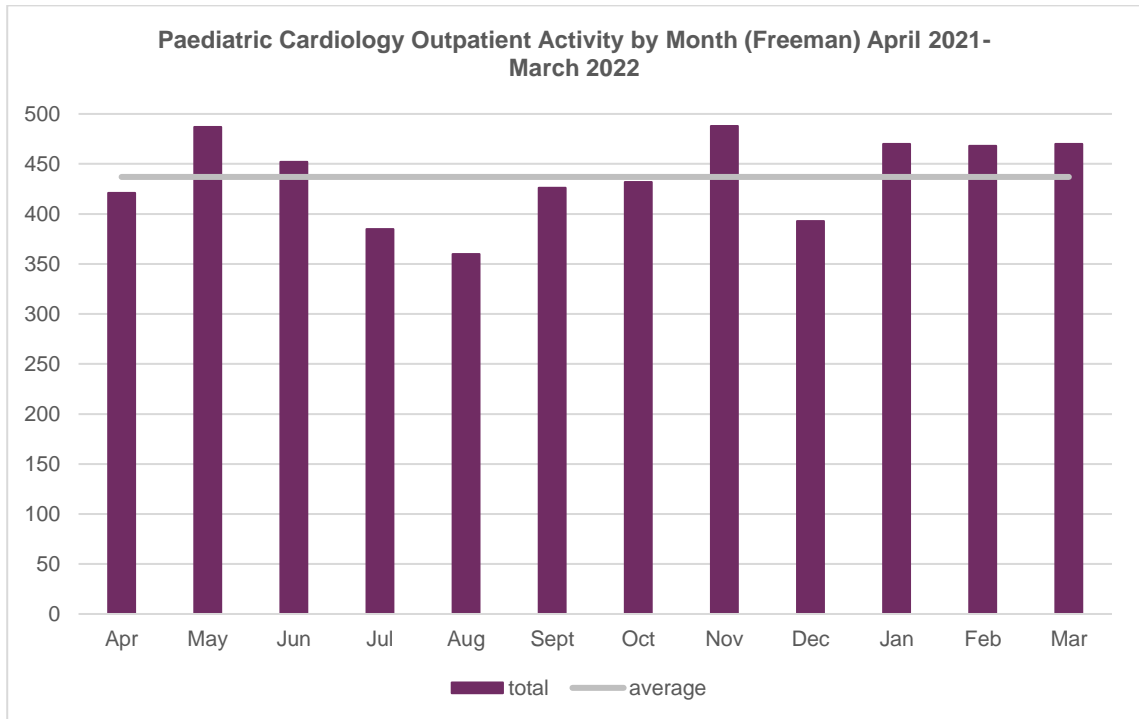


The graph below shows the percentage of paediatric patients who did not attend (DNA) their clinic appointments over the last year which is fairly uniform across the region, the average over the year being 11%. The total number of DNAs was 673 with the highest rate seen for patients from Northumberland (17%), Newcastle (14%) and Durham (13%), the lowest were from the Hartlepool (1%) and Redcar & Cleveland (1%).



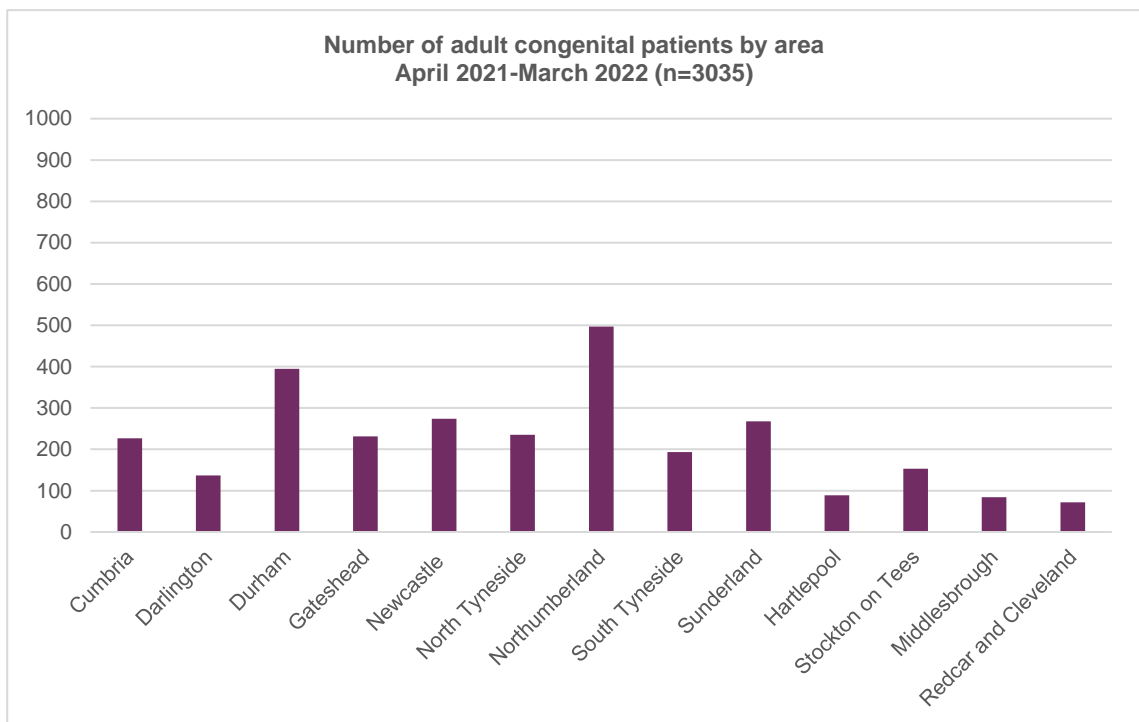
⁶ Information generated by Information Services, NUTH.

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 2021 – March 2022)

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 3035 appointments between April 2021 and March 2022, the largest number of adult CHD patients live in the Northumberland area (497) and the least number from Redcar & Cleveland (72).

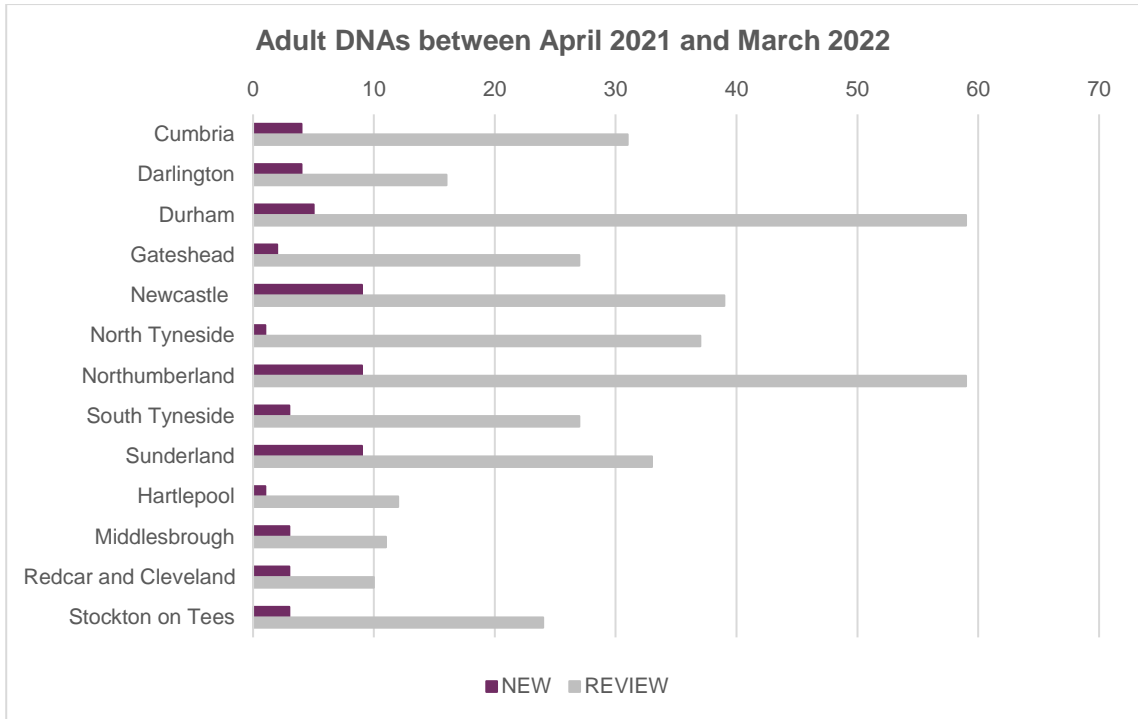


We would also like to represent CHD patients under the care of local teams and will be investigating how to collate this data during our peripheral centre visits to include in future reports.

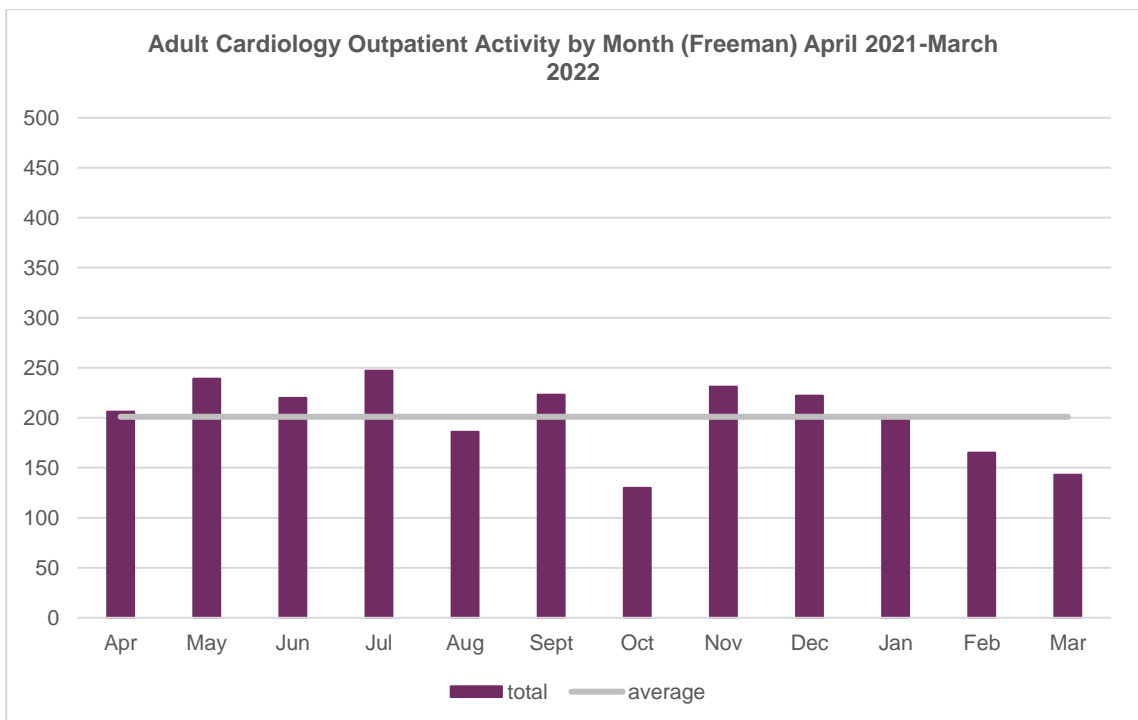
The graph below shows the number of appointments for patients from across the region seen at the Freeman Hospital. Between 1 April 2021 and 31 March 2022 there were 361 new appointments, 2494 review appointments and 441 DNAs.



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.

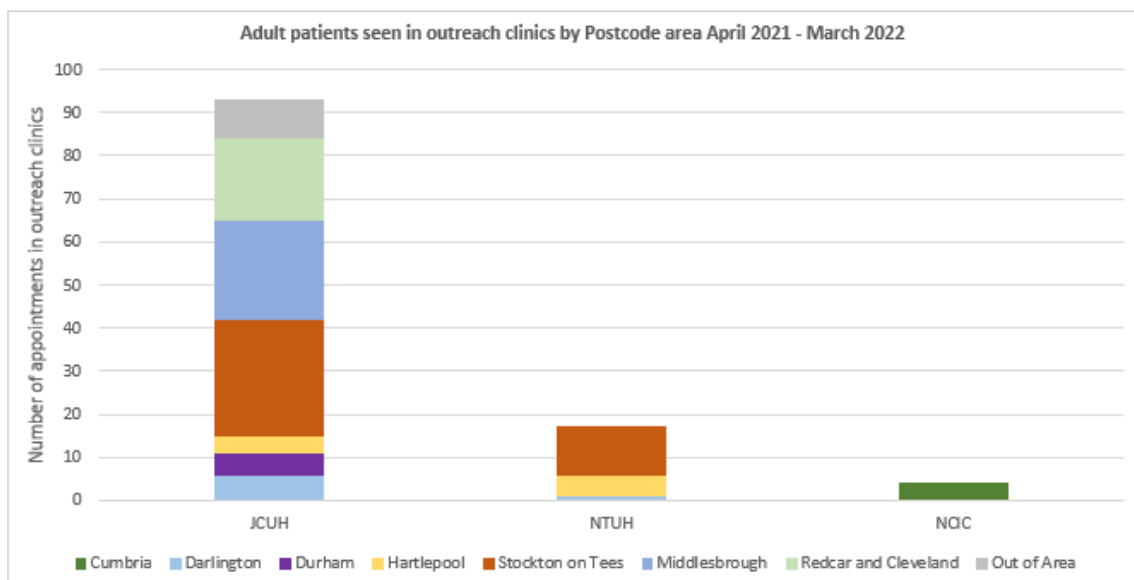
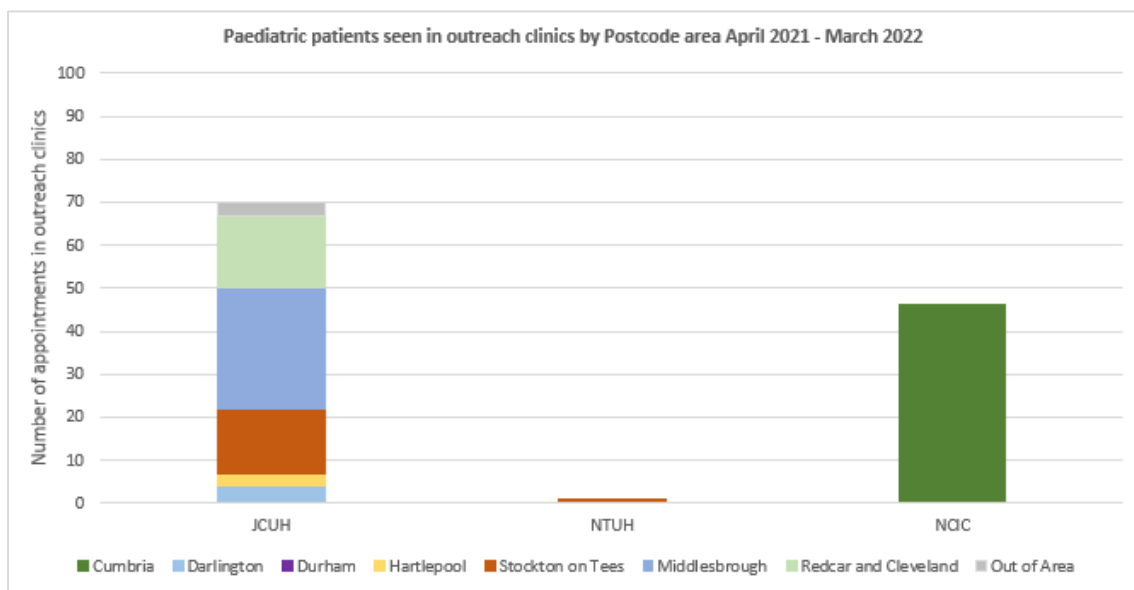


Outreach clinics (April 2021 – March 2022)

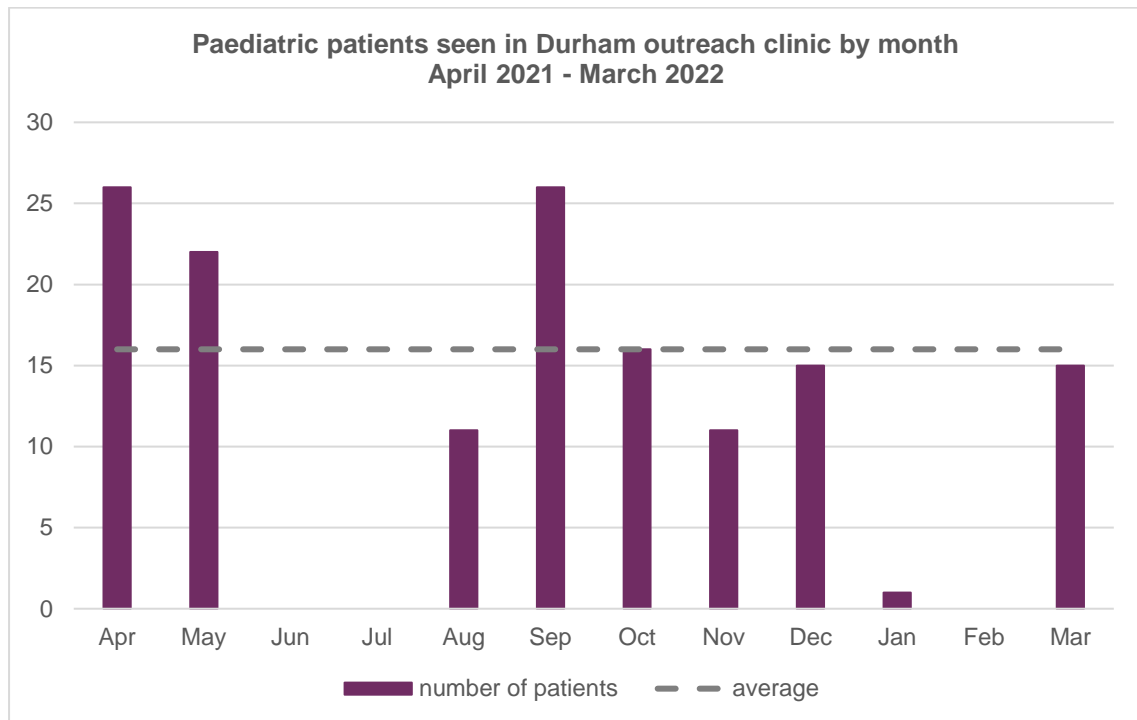
Although the pandemic had a significant effect on the provision of outreach clinics over the last year, many were able to go ahead, some virtually and some face-to-face with reduced patient lists due to covid restrictions.

Newcastle Trust delivers monthly outreach clinics at James Cook University Hospital and North Tees University Hospital for both paediatric and adult patients, and a paediatric clinic at Cumberland Infirmary.

Of the 6145 paediatric appointments between April 2021 and March 2022, 117 were delivered in outreach clinics; and of the 3035 adult appointments, 115 were seen in outreach clinics. The graph below shows a breakdown by postcode area for these attendances.



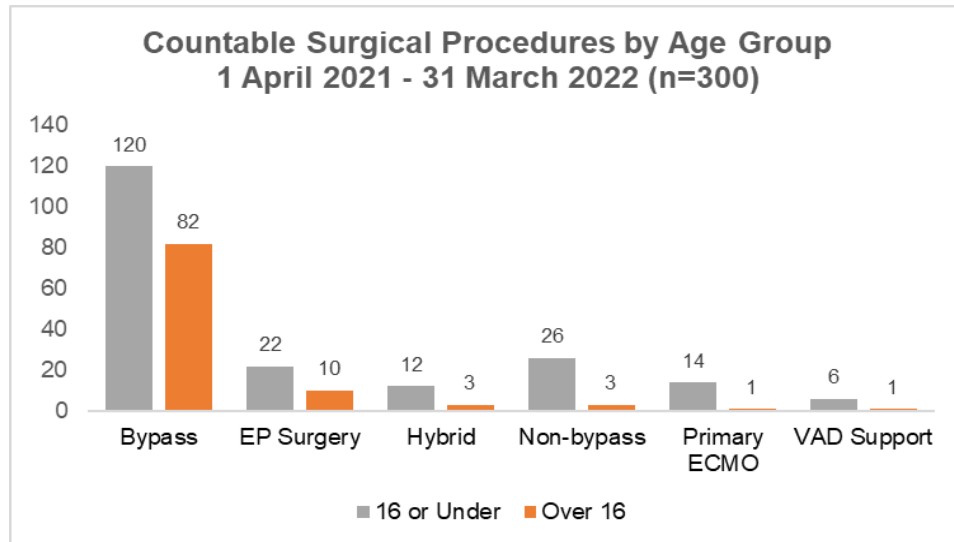
In addition, a monthly paediatric outreach clinic is held at University Hospital of North Durham.



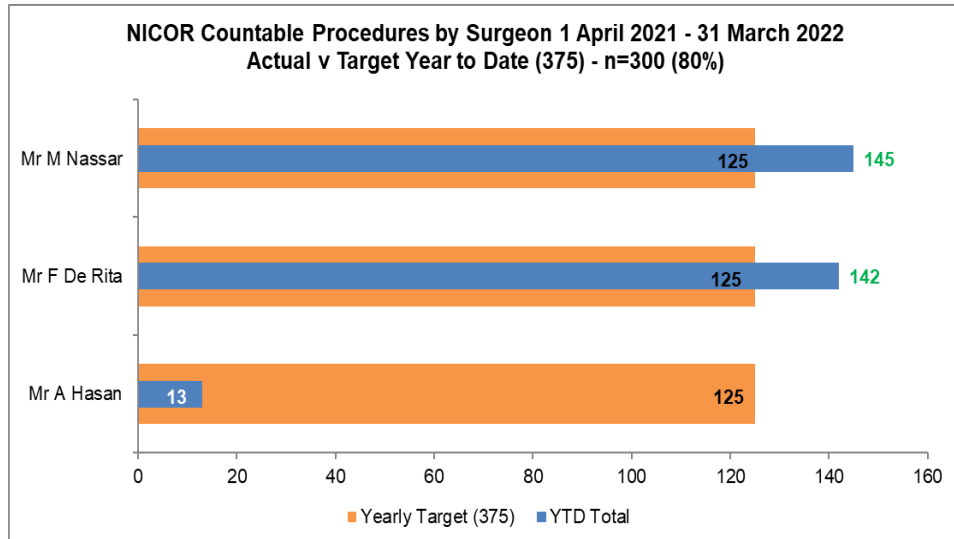
Inpatient Activity (April 2021 – March 2022)

Surgical Activity

The total number of countable surgical procedures carried out in the unit for 2021/22 was 300 which is 80% of the target of 375 procedures.

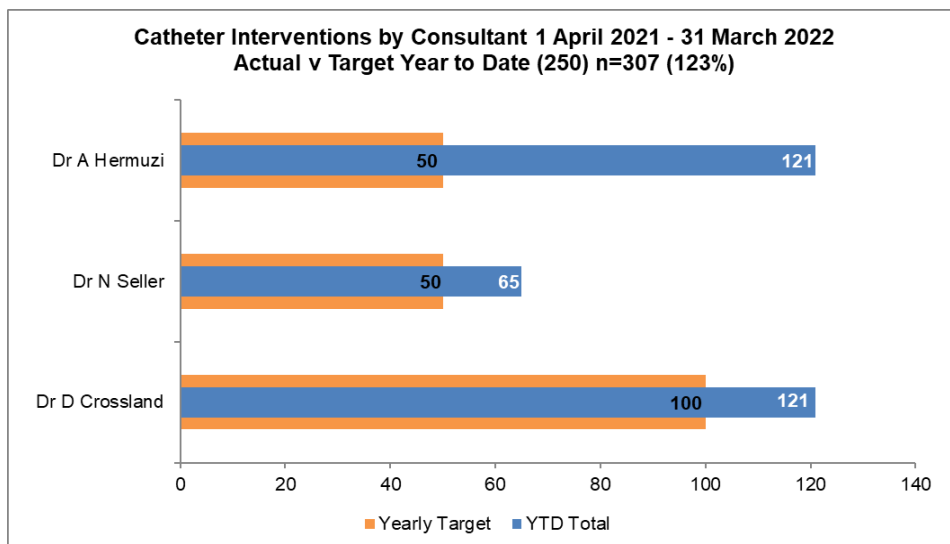
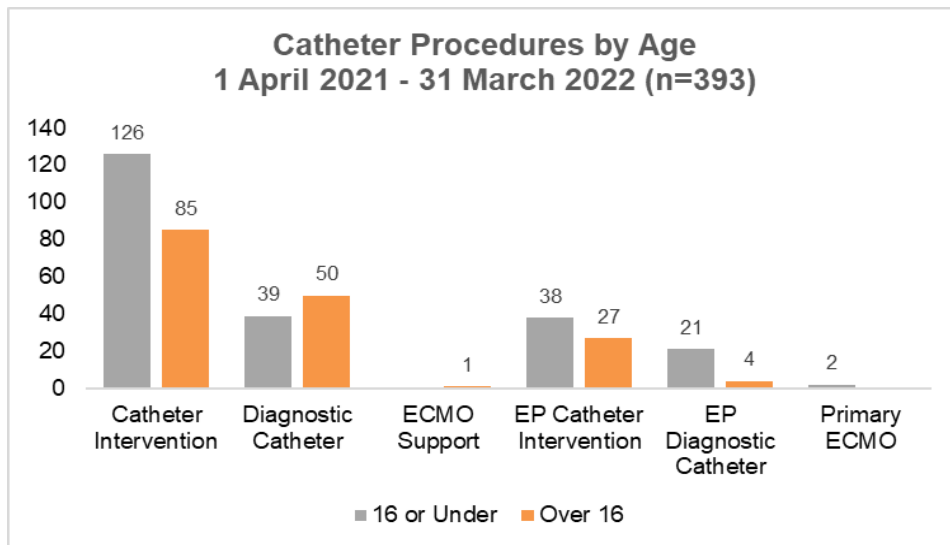


The target for each operator 125 procedures per year, the graph outlines the number of procedures carried out by each surgeon during 2021/22.



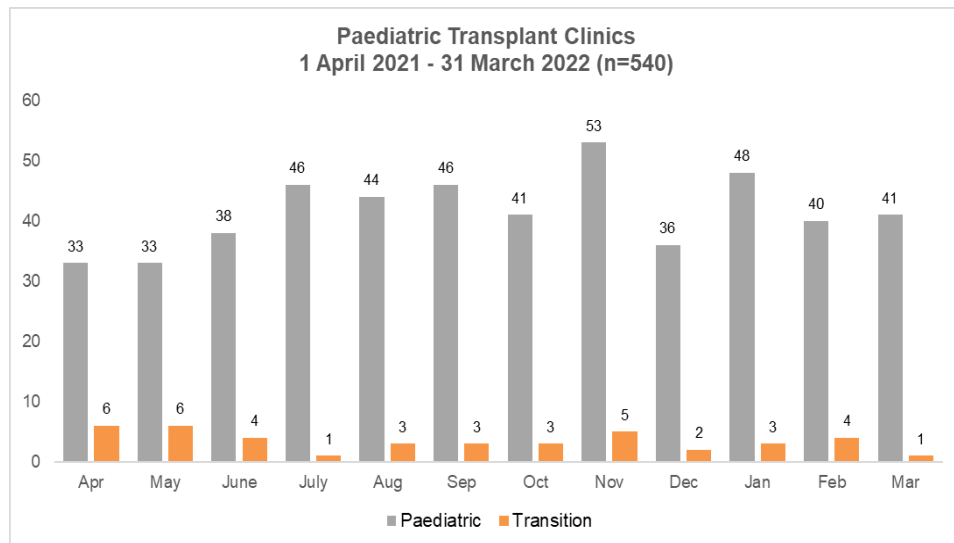
Cath lab procedures

The total number of catheter interventions carried out in the unit for 2021/22 was 393 which is 157% of the target of 250 interventions.

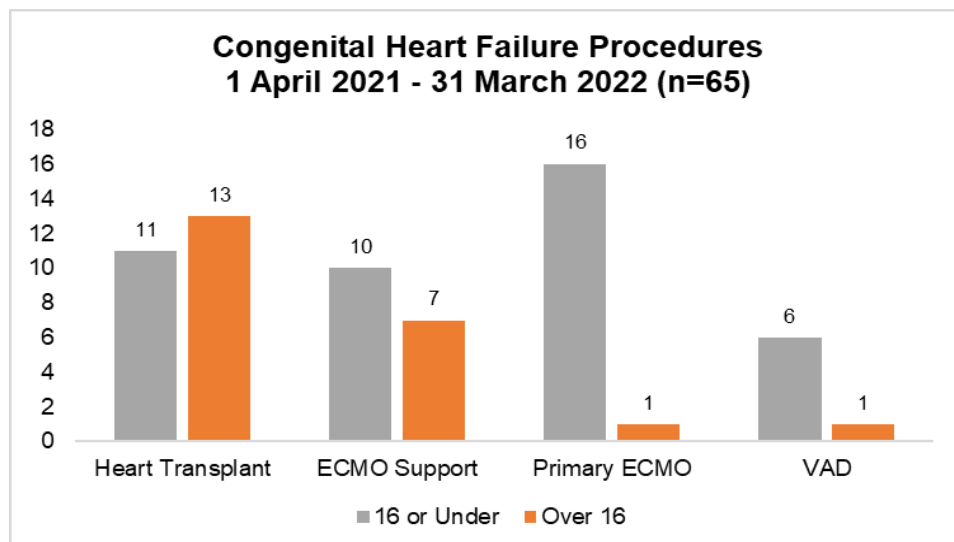


Transplant clinics

The graphs below show the number of transplant clinic appointments and assessments between April 2021 and March 2022, a total of 540 appointments compared to 439 in 2020/21. On average there were 34 paediatric transplant clinic appointments each month.



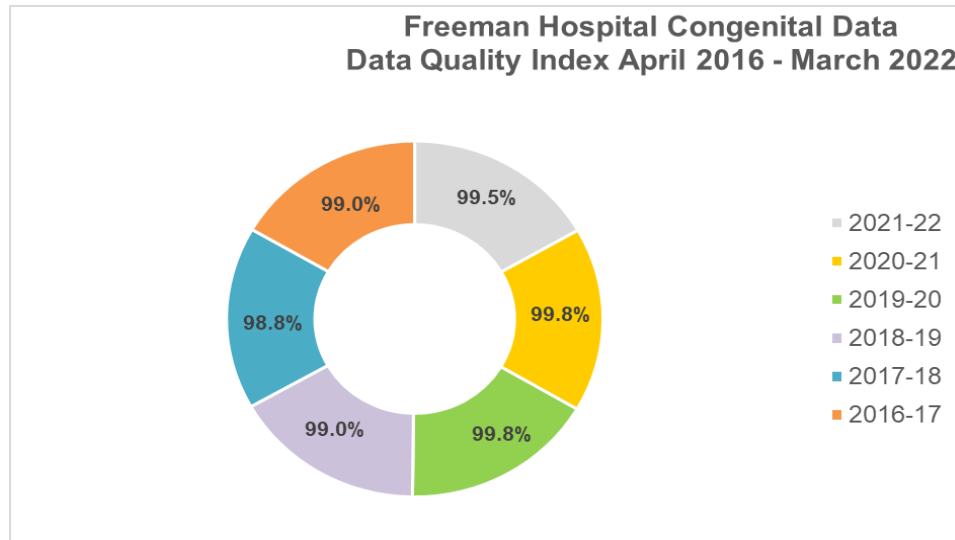
The graph below shows the number of procedures for heart failure patients and transplant patients including the number of VADs, ECMO procedures and procedures involving ECMO. There were 65 procedures in 2021/22 compared to 34 in 2020/21, with the largest increase seen in providing ECMO in the under 16 year group (16 cf. 2).



NICOR DATA 2020/21

Data Quality Index

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%.



NCHDA AT A GLANCE

Data from the period April 2020 to March 2021



During the coronavirus disease (COVID-19) pandemic period there was a considerable fall in numbers of CHD procedures and increased waiting times, along with delays in outpatient appointments and other non-surgical activity. This effect was more pronounced in adults than children.

Number of treatments



There was a 17% reduction in overall activity (surgery, intervention and electrophysiology) with a total of 9,749 CHD procedures on children and adults in 2020/21.



All age groups were affected, with the largest fall in adult procedures (down 44%).

Survival at 30 days



Despite this being one of the most complex areas of surgery, the UK and Republic of Ireland continue to have excellent outcomes with high survival and low mortality rates.

Outcomes after paediatric cardiac surgery continue to show a high 30-day survival rate of over 98%.

Unadjusted raw (crude) 30-day mortality rate dropped to 1.6% of the 3,113 surgical operations undertaken in children under 16 years with a risk adjusted rate showing outcomes are better than expected.

There were approximately 10% fewer deaths than predicted after 30 days across 2,302 adult CHD operations.

Antenatal diagnosis

About 20–30% of congenital heart defects are severe, defined as being potentially life threatening and requiring surgery within the first year of life.



Antenatal diagnosis for all infants requiring a procedure in the first year of life rose to 52% (though variations between centres showing scope for improvement).

Fetal anomaly screening continued nationally despite the pandemic.

Complications after procedures

Post-procedure related complication rates for under-16s show some inter-centre variation.



Average complication rates include: 2.4% requiring life support, 1.5% requiring an unplanned pacemaker, 1.8% with prolonged pleural drainage and 4.1% needing renal replacement therapy (including peritoneal dialysis).

New for 2022/23

SIM baby (Nelle)

SIMBABY, an advanced simulator designed to help healthcare providers effectively recognise and respond to critically ill paediatric patients, has arrived in the region, funded by Northeast charity The Children's Heart Unit Fund (CHUF).

The SimBaby simulator looks and acts like a 9-month-old paediatric patient and provides a highly realistic mannequin that meets specific learning objectives focusing on initial assessment and treatment. Controlled by a trained educator, the new technology can simulate real life scenarios, allowing healthcare professionals to work effectively as a team to deal with life threatening situations.

The equipment costing over £36,000 was largely funded by a donation made by Paige Jones, who raised over £23,000 as part of her 21k for 2021 fundraising challenge in memory of her cousin Nelle. CHUF has named the baby "Nelle" as a lasting tribute and a thank you to Paige who worked extremely hard by hosting fundraising events, organising walks, marathons and bake sales to reach her target.

Nelle will enhance the education programme, set to be rolled out by the North East and North Cumbria Congenital Heart Disease Network across the region for all healthcare professionals, enabling them to confidently manage the care of children with congenital heart disease (CHD) and heart dysfunction, ensuring a safe pathway of high-quality care within the Northeast and North Cumbria.

Kaye Walsh, Lead Nurse Congenital Heart Disease Network, said: "My role as an educator allows me to work collaboratively and effectively with teams of professionals in the region, including those who may not be exposed to CHD patients daily.

"With the ability to imitate clinical situations and trigger Nelle's ultra-realistic physiological responses, I can ensure that healthcare providers are exposed to a range of possible scenarios, such as irregular heart rate and rhythm, heart failure and undiagnosed congenital heart disease infant presentation. The first time doctors and nurses encounter a baby with these symptoms can be stressful, by training with SimBaby we allow them to experience how they would respond as a team in a safe environment when presented with a real-life scenario. "Nelle" reacts as a real baby would which means the emotional responses of the doctors and nurses carrying out the training is a lot more visceral, embedding the information more deeply than more traditional 'PowerPoint' style training techniques.

"Having access to equipment such as this, as well as the ongoing support from CHUF, means that we can continue to elevate NHS healthcare team training and deliver the very highest quality of care for all patients with CHD across the lifespan of the disease."

CHUF provides support to the children and families who receive treatment at the Children's Heart Unit based at Freeman Hospital by funding large and small pieces of equipment, facilities, aftercare, support services, specialist staffing and research. Working closely with the NENC CHDN, CHUF are extending their support across the region to benefit heart patients across the whole of the North East and Cumbria.



SIM training programme

Kaye has started a SIM training programme across the region and has visited 3 Trusts so far. The training has been delivered to Gateshead, County Durham and Darlington and Carlisle teams, delivering hands-on bespoke training on cardiogenic shock management for a baby presenting with un-diagnosed congenital heart disease, with the support of one of the registrars from the Freeman, Nicola Boyd.

We have also delivered cardioversion hands-on training whilst on site during the sessions as requested by the teams. This has been very well received. Teams have asked for further ECG and arrhythmia education. We are planning to deliver an education workshop for the network teams in early October.

Feedback from the programme has been very positive and we are outlining additional dates for 2023.

Cardiac Simulation Training 12/05/2022

The cardiac simulation day was a great success amongst the paediatric A&E staff at the Queen Elizabeth Hospital.

Before doing this simulation the staff were not confident when looking after a cardiac patient on the ward it was a “scared of the unknown” situation. The staff that took part in this simulation were much more confident around the care of a child with a CHD and had more of a basic knowledge around the general presentations of undiagnosed CHD in children. It allowed them to understand the main signs and symptoms and learn the appropriate treatment and observations that they may need to carry out. After this simulation the staff were more positive and confident when talking about a child presenting with CHD. Staff have also asked myself to organise a skills/training day to have a more in depth training day on CHD and the staff that were unable to make the simulation were keen to try and attend one at another time.

Overall the teaching we received that day has massively boosted the attitude and confidence of the staff and has encouraged others to take part in further training that may be arranged.

Becca Williams
Staff Nurse QEH/Cardiac Link nurse

Cardiac rehab training

The Network team have been invited to join the cardiac rehabilitation team and attend there quarterly meeting. We are working with the team to deliver both bespoke cardiac rehab training for CHD patients and will be running a half day training event in January 2023.

ECHO course

The Network team helped to facilitate the second paediatric ECHO course in May 2022. This course will run again in early 2023 and has been extended to include training in adult CHD ECHO and will run for 3 days.

CHD Certificate

We are in final stages of developing the programme of education for nurses, ODPs and AHP's in collaboration with the Newcastle Hospitals Skills Academy. The Certificate of Achievement in Improving Clinical Practice in Congenital Heart Disease will be open to registrants early 2023.

This course will aim to enhance knowledge and skills in the care of patients from birth to adulthood living with congenital heart disease. This face-to-face course is an exciting addition to education accessible to our regional colleagues and indeed nationally.

Publications

Ambulatory Care in Adult Congenital Heart Disease-Time for Change?

Coats L, Chaudhry B. *J Clin Med*. 2022 Apr 6;11(7):2058. doi: 10.3390/jcm11072058.

Gender differences in the assessment, decision-making and outcomes for ventricular assist devices and heart transplantation: An analysis from a UK transplant center. MacGowan GA, McDiarmid A, Jansen K, Coats L, Crossland D, Woods A, Kunadian V, Shah A, Schueler S, Parry G. *Clin Transplant*. 2022 Jun;36(6):e14666. doi: 10.1111/ctr.14666.

Ventricular assist devices in transposition and failing systemic right ventricle: role of tricuspid valve replacement. Gonzalez-Fernandez O, De Rita F, Coats L, Crossland D, Nassar MS, Hermuzi A, Santos Lopes B, Woods A, Robinson-Smith N, Petit T, Seller N, O'Sullivan J, McDiarmid A, Schueler S, Hasan A, MacGowan G, Jansen K. *Eur J Cardiothorac Surg*. 2022 Mar 4:ezac130. doi: 10.1093/ejcts/ezac130.