

# East Midlands Congenital Heart Network

Annual Report  
2021-22



**NHS**  
East Midlands  
Congenital Heart Network

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# Foreword

It was easy to lose track of time during the Covid pandemic with fewer reference points to give a sense of time and place. The clear exception to this was the East Midlands Congenital Heart Centre (paediatric) move from Glenfield to LRI in August 2021. This was a key moment in history for CHD services in the East Midlands as it ignited a project to create a new children's hospital in the region. This not only corrected a longstanding disconnect between the care of heart problems and the care of the whole patient, it also satisfied a key demand of leaders of the national CHD strategy. Without this co-location, they said, there could be no tertiary paediatric cardiology and ACHD care in the region.

Of the three hospital trusts who faced this ultimatum, UHL were the first to complete by a country mile. The team have since been delighted to share their experience with colleagues from the Freeman Hospital Newcastle who are now on the same journey. The team at UHL should be immensely proud that they completed this project under the duress of severe budgetary constraints and a global health emergency. It was a carefully choreographed dance of clinicians, managers, estates teams and charities that would have the Strictly judges on their feet.

The reason that this project deserves mention at the top of this report is that it secures a world class facility for everyone in the region affected directly or indirectly by congenital heart conditions be they from the Peaks of Derbyshire, the wolds of Lincolnshire or the Nene valley. Excellence in the Level 1 centre in turn helps support the excellence in cardiac care we see every day in all the partner organisations of the Network, and vice versa. As a network we are now not simply in a position to train some of the best only for them to fulfil their professional ambition elsewhere but to be an importer of skills, knowledge and talent because people see their future here.

As we look forward to the year ahead, the Network would like to build on this incredible work and strengthen our ties even further. There will be a big push to bring us together through a number of exciting education and training events. We will go beyond EMCHN and develop a "network of networks" that highlights the interface between cardiac care and care delivered by other specialties. Keep an eye on email inboxes and our beautiful new EMCHN website for details.



**Aidan Bolger**  
Clinical Director  
East Midlands Congenital Heart Network



# Our Network

## East Midlands Congenital Heart Network

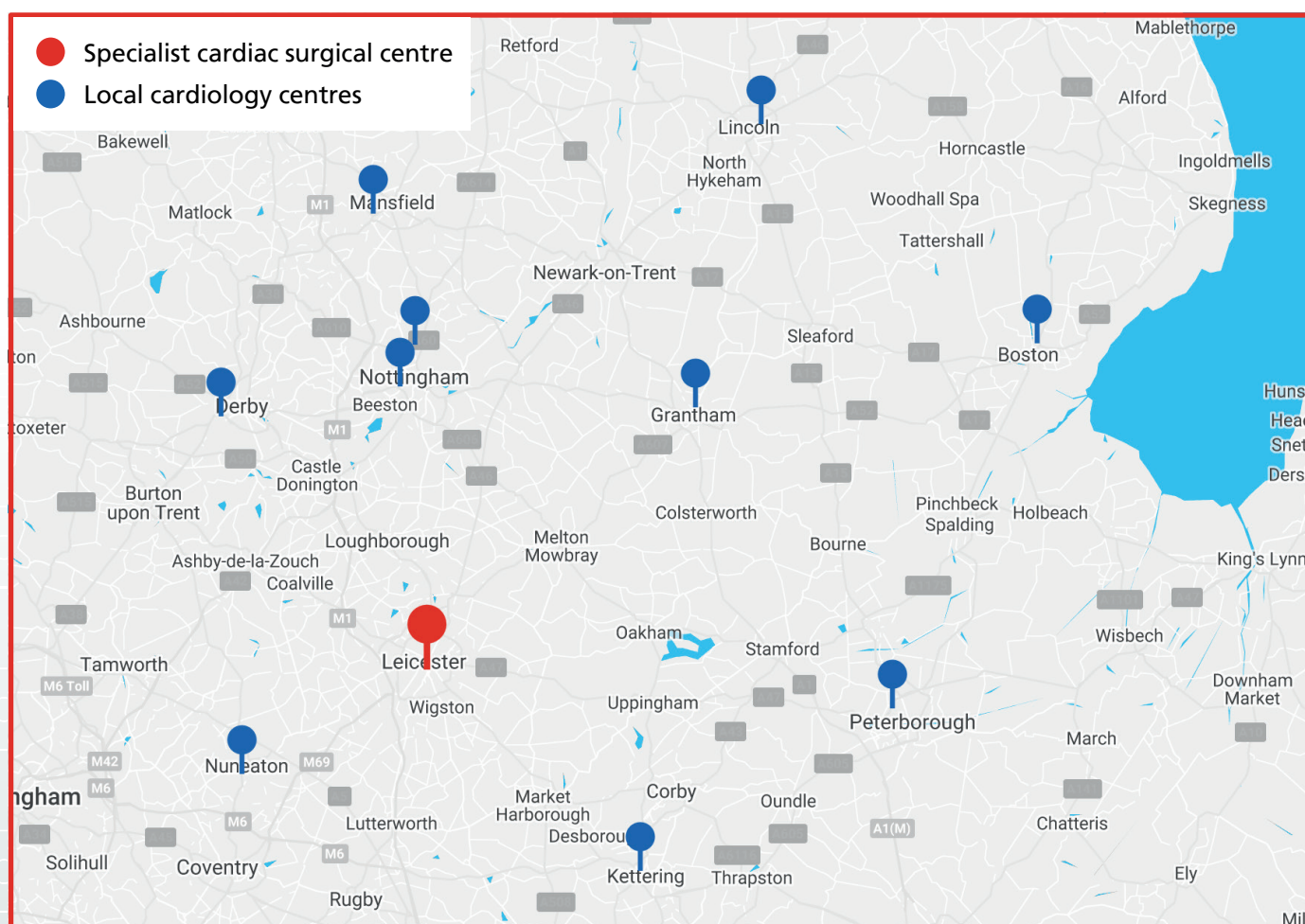
### Geography

The East Midlands is one of nine official regions of England with an estimated population of 4,865,583. The network region comprises the counties of Derbyshire, Leicestershire, Lincolnshire (except North and North East Lincolnshire), Nottinghamshire and Rutland, as well as parts of Cambridgeshire (Peterborough) and Warwickshire (Nuneaton).

### Model of Care

The East Midlands Congenital Heart Network comprises **1 specialist cardiac surgical centre** and **10 local cardiology centres**.

The dedicated level 1 specialist centre of care, delivers a streamlined pathway approach to both Adult and Paediatric congenital heart care. Accompanied by a range of local level 3 centres across the region, we are also able to deliver lifelong care closer to home.



# Our Network



**12**

Hospitals



**17**

bedded Children's  
Cardiac Ward



**12**

bedded Cardiac Paediatric  
Intensive Care Unit



**6**

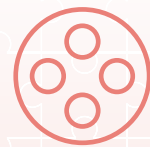
respiratory and cardiac  
ECMO service



Outpatient services for  
children and adults in 15  
dedicated clinics across the  
level 3 centres every month



Children's Cardiac Hybrid  
Catheter Lab



Children's Cardiac Theatre



# Our Network Clinicians



**11**

Consultant Paediatric  
Cardiologists



**3**

ACHD Cardiologists



**10**

Paediatricians with  
expertise in Cardiology  
(PECs)



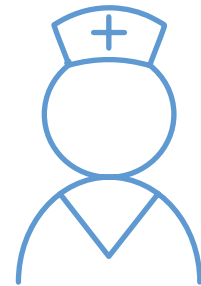
**8**

Cardiologists with  
Interest in ACHD



**3**

Consultant Surgeons



**9**

Specialist Cardiac Nurses  
(six paediatric,  
three adult)



**2**

Paediatric  
Pharmacists



**4**

Psychologists  
(three paediatric,  
one ACHD)



**11**

Congenital Cardiac  
Physiologists



# Our Network Activity

	2020-21			2021-22		
	Adult	Paediatric	Total	Adult	Paediatric	Total
Surgical Procedures	36	151	187	41	204	245
Catheter Procedures (inc Eps & Hybrids)	28	83	111	69	124	193



**1476**

Total number of outpatient's clinics held across the Network



**426**

Total number of outpatient's clinics held within our level 3 peripheral hospitals



**1050**

Total number of outpatient's clinics held within our Level 1 Centre





# East Midlands Congenital Heart Operational Delivery Network

The East Midlands Congenital Heart Network's role and function is to enable and support a collaborative and seamless approach to congenital heart disease patient care across the East Midlands, ensuring that the services delivered are of a high quality and that the provision of care is equitable across the region.

## Vision

The network vision demonstrates the collective ambitions that the EMCHN strives to achieve.

- Seamless approach to the provision of care across the Network
- Equitable access to services regardless of geography
- Care as close to home as possible
- Access to meaningful and high quality information
- Culture of collaboration
- Ambition to continually improve services

## Objectives

Through the delivery of an annually agreed programme of work the network will support the delivery of both regional and national priorities. This will be based on the assurance that we will:

- Provide strategic direction for congenital heart disease care across the East Midlands
- Support the overall vision of the Network
- Agree key priorities for areas of improvement
- Support education, training and development
- Provide a central point of information and communication for Network stakeholders

## Network Programme of Work

The Network will develop an annually agreed programme of work which will support the delivery of both regional and national priorities, ensuring that a collaborative system wide approach is achieved with a clear focus on consistent high quality, evidence based service provision enabling optimal patient care and experience.

The Network programme aims to:

- Identify priority areas to promote and support the development of Congenital Heart Disease services
- Focus on the delivery of high quality care in line with CHD Standards, with an emphasis on ensuring equitable provision of services and a seamless transition in care across the whole patient journey
- Development and/or implementation of the Network's quality and safety agenda, which is aligned to evidence-based practice ensuring consistent policies, procedures and guidelines are adopted
- Develop data intelligence to inform service improvement and system-wide change
- Facilitate integration between the Network Strategy and the wider healthcare agenda
- Foster a culture of clinical and patient/public engagement in the development and review of congenital heart disease service provision.





## East Midlands Network Management Team

The East Midlands Congenital Heart Network works to bring clinical teams, managers, commissioners and patient/family representatives from across the region together to support patients of all ages with a congenital heart condition, and their families/carers.

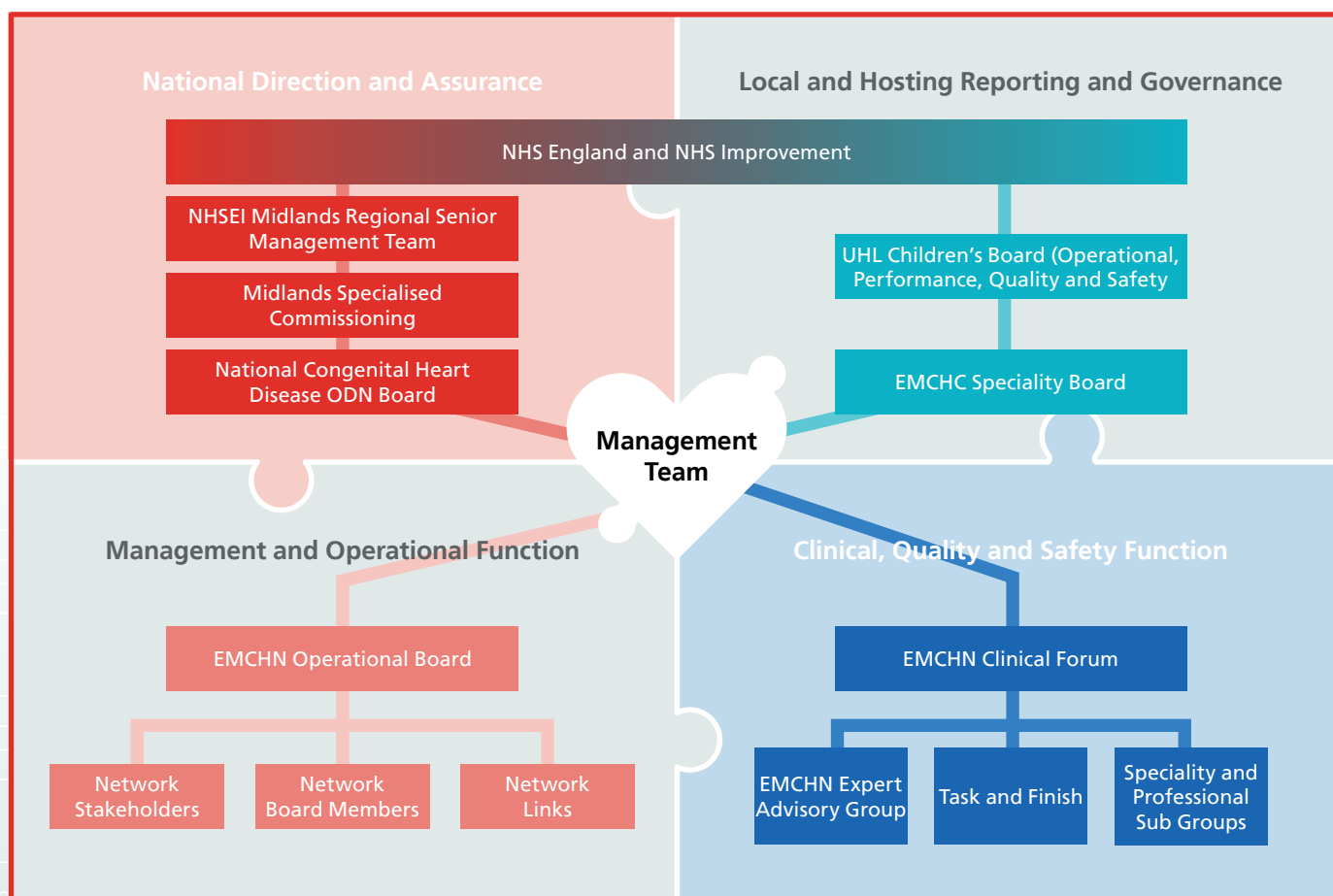
## East Midlands Operational Network Board

The purpose of the EMCHN Board is to oversee the effective operational

development and delivery of congenital heart disease services across the East Midlands region, ensuring a collaborative approach to safety, quality and equity of care is achieved.

The aim of the Operational Board is to oversee the development of a shared vision and agreed strategy for congenital heart disease services across the East Midlands.

The Board will utilise an advisory and facilitative function to make recommendations based on the CHD standards, supporting and advising stakeholder organisations on how best to plan, commission and deliver congenital heart disease services whilst ensuring NHS England direction, strategy and guidance is considered.



## Host Provider

EMCHN continues to be hosted by the University Hospitals of Leicester. The host organisation provides a business support role to the network which includes:

- Financial accommodation for the allocated Network agreed budget through NHSEI
- Office and IT facilities
- Human resource support for the Network management team
- Agreed governance role within the Network Operational Board

## Financial Position

The East Midlands Congenital Heart Operational Delivery Network is funded by NHSE Specialised Commissioning services. The funding agreement is aligned to a contractual agreement which ensures we deliver the set requirements outlined for

operational delivery networks.

Full allocation of network funding covers:

### Staffing establishment

- Clinical Director
- Network Manager
- Network Lead Nurse
- Network Administration Manager

### Non Pay Cost

- Travel
- Hosting overhead
- Delivering programme of work

Due to intermittent staffing vacancies a projected underspend for the network budget had been accrued.

The Network Board agreed for this to be spent on the development of the EMCHN website, training and education and any resources which would be beneficial across the network.

## Continuation of the Congenital Heart Disease Operational Delivery Network (CHD ODN)

### Staffing

Network Manager	8a	1	<b>£58,955</b>
Network Nurse	8a	1	<b>£58,955</b>
Network Administrator	5	1	<b>£35,448</b>
Consultant time		2 sessions	<b>£13,964</b>

**Total Staffing Costs** **£167,322**

**Travel** **£14,060**

**Total Direct Costs** **£181,382**

**Overheads (10%)** **£18,138**

**Total Cost** **£199,520**



# 2021-22 Network Highlights

## Network Lead Nurse update

Over the last year, a Nurse's Clinical Forum has been developed across the East Midlands Congenital Heart Network. The meeting brings together nurses to share best practice and consider how collaborative working can support and improve staffing, training, quality, safety and patient engagement that affects patients with congenital heart disease and their families. Meetings so far have been attended by nurses from various clinical areas including neonates, outpatients and community settings. Work plans will be fed back to the operational board for scrutiny.

Work to support outreach clinics continued with face-to-face clinics continuing in all centres for both paediatric and ACHD services. Visits to Network hospitals identified challenges and risks faced and tried to offer solutions where possible. Key stakeholders and nursing contacts were identified in order to plan education and training.

Over the next year, I have ambitious plans to further build on the Nurses Clinical Forum working on increased engagement. I will continue visits to clinical areas such as Network Hospitals and community settings to increase visibility, support teams with challenges of restoration and recovery and build on the Network Education strategy. I will be communicating with clinicians, stakeholders and patients using a variety

of platforms to promote our educational programme, improve service delivery and enhance signposting of CHD related support. This will include promotion of the new EMCHN website, development of new patient information leaflets and network newsletters.

A major new project for the Network in the coming year will be to gather patient feedback through outpatient questionnaires and the formation of a patient representative group. This will enable our service users to make valuable contributions to how we can improve standards of care and patient experience within our Network.

## Education & Training

A core objective of the EMCHN is to support and promote our healthcare professionals with education and training opportunities. The ongoing challenges of the COVID -19 pandemic affected many of our clinical services. Due to this, much of our training and education was delivered online using various platforms. An advantage of this was that it allowed network-wide participation without the constraints of geographical distance. Having said this, the Network is keen to increase the number of face to face educational events in the coming year and develop a hybrid option using the latest web-based technologies.



## Highlights of the last year include

- Delivery of two nursing study days in collaboration with many of the CHD Network Lead Nurses offered to a national audience. Over 140 delegates attended online on each occasion. These were collaborative events between Lead Nurses from Yorkshire & Humber, North East, North West and South West CHD Operational Delivery Networks. The first session covered common CHD lesions, surgical pathways, interventional pathways, palliative care, transition and lifestyle choices and working with networks and signposting to charities. The second focussed on the management of patients with tetralogy of Fallot.
- Session on interventional cardiology ahead of new cardiac catheter laboratory opening in Level 1 Centre. This was a wonderful amble through the evolution of paediatric cardiac catheterization, the journey of the East Midlands Congenital Heart Centre from its beginnings at Groby Road Hospital and the future perspectives of interventional catheter procedures. The talks were presented by eminent national and international cardiologists facilitated by Dr Rizwan Rehman.
- Secondment of 20 nurses from EMCHN to 18th Introduction to CHD course over 5 study days hosted by the London CHD education teams. The course was aimed at nurses and AHP's giving participants a combination of live webinars, discussion forums, e-learning and didactic sessions. Topics covered antenatal diagnosis through to living with congenital heart disease as an adult. Common lesions, surgical management of both cyanotic and acyanotic defects and transitional care were covered. It gave a broad overview for any professional caring for patients with CHD.
- Bi-Annual Educational Events with summer talks on PIMS-TS, PDA Controversies, an overview of Neonatal ECG & Arrhythmias. The winter training day topic was assessment, management and treatment of heart failure. This event was attended virtually by clinicians, physiologists, perfusionists, nurses and AHP's working throughout the Network.
- EMCHN was able to support two cardiologists and one Paediatrician with Expertise in Cardiology to attend a two day course in Newcastle on Paediatric Congenital Heart Disease Echocardiology course. The course covered all facets of paediatric congenital cardiac echocardiography, providing comprehensive learning through case based lectures



## Network Psychology Update

The psychology team has enjoyed a return to a more normal way of working over the last year. Outpatients are increasingly seen face to face, and we are back supporting children and families in the inpatient areas at the LRI. We have said goodbye to Dr Oonagh O'Hare and welcomed Dr Melina Throuvala to the team.

We are making increasing use of the fabulous new EMCHN website as a hub for materials for professionals and families. It is a key source of information for a wide range of service users from across the network. You can find helpful tips on supporting children with common difficulties, details of how to refer to the service and much more. Videos introducing the psychology service will soon be added alongside advice to help children adjust to the challenges of their heart condition and the treatment they may need. We know prevention of psychological distress is better than a cure.

The Network education event in March 2022 gave us the opportunity to talk to our colleagues about the role of the psychology service and this was followed by a lively Q&A session. Please let us know if there are particular topics you would us to cover in future talks.

Our service evaluation of the Neurodevelopmental Outreach Programme is drawing to a close and we hope to be able to present our findings in the coming months. Indications are that early psychological intervention is an important determinant of patients having positive experiences of hospital treatment. Those with complex heart conditions are at the highest risk of having additional needs and require focussed support.

Referrals to the psychology service from network consultants are not as high as we anticipated. We are keen to hear from you about why this might be. Please note that we are happy to receive clinic letters with the relevant information, rather than the referral form if that is easier. The Network team can provide patient information leaflets for your outpatient areas and an electronic version can also be accessed the UHL YourHealth hub: <https://shorturl.at/cjqJQ>

We look forward to updating you in 12 months and in the meantime we are always happy to hear from clinicians who would like to discuss their patients and make a referral to the service.





# Network highlights



## Relocation of Level 1 Paediatric Congenital Heart Disease Services

The paediatric component of the East Midlands Congenital Heart Centre has now relocated to the new Children's Hospital development at the Leicester Royal Infirmary site. This exciting move forms part of a wider service development approach within the University Hospitals of Leicester NHS Trust. Part of this first phase has brought cardiac paediatric services together on what will become a new single-site Children's Hospital.

This development has enabled a seamless approach to all aspects of paediatric cardiac care and co-locates the East Midlands Children's cardiac services with the rest of paediatric specialities, conforming to NHS England Service Specifications.

The provision of adult congenital heart care remains with the adult component of the East Midlands Congenital Heart Service at Glenfield Hospital.



# Network communications

## Website Launch [emchnetwork.nhs.uk](https://emchnetwork.nhs.uk)

We are pleased to announce the launch of the new dedicated East Midlands Congenital Heart Network website. This exciting development provides a centralised resource for both service users and the clinical teams. Each section is designed to support individuals through their patient journey with designated easy- to- access sections. The website will be continually developed, with bespoke videos to be added shortly.

## Twitter @EMCHNetwork

Our twitter account continues to share weekly tweets, real time promotion of key information and resource signposting.

## Network Quality Data dashboard

The first phase of the network data quality dashboard is now in use. The aim of the data collection tool is to demonstrate equity of care across the network, including themes such as waiting times for outpatients, referral to treatment (RTT) timescales and staffing provision. This first phase focused on waiting list times and additional elements will be added as data compliance becomes more stable. We continue to work with all trusts across the network to ensure data is submitted consistently each month and organisations understand the benefit and outcomes of this dashboard.

## Network Risk and Incident reporting

One of the objectives set for 21/22 was to agree and implement a risk and incident reporting process, promoting shared learning through Board and clinical meetings. As a result the Network has implemented a specific network focused risk and issues register. The register aims to capture key themes to support and overcome challenges which impact the care delivered across the Network.





# 2022 – 2023 Forward Focus

Looking forward to 2022 – 23 the Network continues to focus on the seven key overarching network objectives, as well as building on the process and strategies achieved during 21-22.

-  To provide strategic direction for CHD care across the East Midlands
-  To monitor and drive improvements in quality of care
-  To support the delivery of equitable, timely access for patients
-  To support improvements in patient and family experience
-  To support the education, training and development of the workforce within the Network
-  To be a central point of information and communication for Network stakeholders
-  To demonstrate the value of the Network and its activities



# Key Priorities

## Network engagement

We have developed a number of mechanisms which allow stakeholder to engage with the network, however we recognise that more work needs to be done to ensure a consistent membership is achieved at the Network Operational Board meetings. Through the review of the network communication strategy we aim to develop additional forums and contacts to deliver the required board objectives.

## CHD standards review and service developments

The planned CHD standards of care review will now take place during the 22/23 programme of work. The process aims to provide a baseline assessment of the network with individual organisations having the opportunity to highlight any key areas which may require additional support or development.

## ACHD capacity and demand

We will be preparing to undertake a project to develop a network-wide understanding of ACHD capacity and demand within the East Midlands. This aims to feed in to the national priorities around adult congenital heart services and support local service development models.

## Network Policies and Guidelines

The process to move all network and CHD related policies, pathways and guidelines to the network website will commence during 22/23. A library of documents will be developed to ensure that all resources are managed in line with agreed review and ratification processes. The network will also offer support in the development of any new required documents.

## Educational strategy

To ensure that the educational needs across the network are addressed, a new educational strategy for the network will be developed. This will comprise a needs analysis tool which will inform the creation of a comprehensive training package available to all clinical workforces.

## Patient involvement and engagement

We have identified a clear gap for patient engagement and involvement across the network. This key area of development will ensure that opportunities are identified to allow service users to share their experiences and thoughts to shape service developments and improvements.



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# Glossary/ additional information

## Specialist Cardiac Surgical Centres (level 1)

Each network will have at least one Specialist Surgical Centre. All cardiac surgery and most cardiological interventions will be undertaken at these level 1 centres. These centres will provide the most highly specialised diagnostics and care.

## Local Cardiology Centres (level 3)

Local children's cardiology centres mainly sited in (District General Hospitals) will employ a paediatrician with expertise in cardiology (PEC) to provide ongoing monitoring and care. They will run outpatient clinics alongside specialists from the Specialist Surgical Centre. This will mean that more care can be given locally, so children and their families will have less need to travel long distances for their ongoing monitoring and care.



# Abbreviations

<b>ACHD</b>	Adult Congenital Congenital Heart Disease
<b>AHP</b>	Allied Health Professional
<b>CHD</b>	Congenital Heart Disease
<b>CPICU</b>	Cardiac Paediatric Intensive Care Unit
<b>DGH</b>	District General Hospital
<b>ECMO</b>	Extracorporeal Membrane Oxygenation
<b>EMCHC</b>	East Midlands Congenital Heart Centre
<b>EMCHN</b>	East Midlands Congenital Heart Network
<b>ICU</b>	Intensive Care Unit
<b>MDT</b>	Multi-Disciplinary Team
<b>MOU</b>	Memorandum of Understanding
<b>NHS</b>	National Health Service
<b>NHSEI</b>	National Health Service England Improvement
<b>ODN</b>	Operational Delivery Network
<b>PEC</b>	Paediatrician with Expertise in Cardiology
<b>PICU</b>	Paediatric Intensive Care Unit
<b>PPI</b>	Patient and Public Involvement
<b>UHL</b>	University Hospitals Leicester





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**East Midlands**  
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