

East Midlands Congenital Heart Network

Annual Report
2020-21



NHS
East Midlands
Congenital Heart Network

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Foreword

It goes without saying that the period that this report covers was an incredibly difficult and disruptive time. So apologies if you've been waiting with bated breath to receive the Network's 2020-21 data and accounts. As you will see, the pandemic had a major impact on the clinical activity within EMCH Network. In fact, we now know that our programme of care was more disrupted, in terms of operations and catheter procedures, than any other network in the country. This was due to Glenfield Hospital having a national role in providing ECMO treatment as well as being home to the Level 1 paediatric cardiac surgical and catheter programme. The paediatric intensive care unit was given over to looking after patients with Covid and the PICU nurses and others went above and beyond to ensure that those most in need received the best possible care.

The pandemic has required us all to work differently but colleagues from all Network centres made sure that congenital cardiac services in the East Midlands kept going and by necessity saw many more patients and families face to face in clinic than many other specialties. The Glenfield service moved not just once but twice to the Royal Infirmary site in order to keep the show on the road and we are indebted to the team at Birmingham Children's Hospital who without hesitation or fuss picked up the care of East Midlands patients in our hour of need.

Now as we are moving slowly but surely away from the dangers of the pandemic and restrictions are being lifted, the Network emerges stronger and more united. As you will see, we have an ambitious programme of training and educational events, a new website and even a Twitter. The Network also has a new focus on supporting additional clinic activity to ensure that all patients, wherever they live, have equitable and timely access to our brilliant team.

I will leave an update about the reorganisation of care in Leicester to the next annual report, but I can say now, (spoiler alert), that despite the ongoing challenges in all our network hospitals, we are now caring for more patients in our clinics than ever before and our surgical and catheter programmes are heading back to pre-pandemic levels. Well done and thank you to all those that are making this happen.



Aidan Bolger
Clinical Director
East Midlands Congenital Heart Network



Our Network

East Midlands Congenital Heart Network

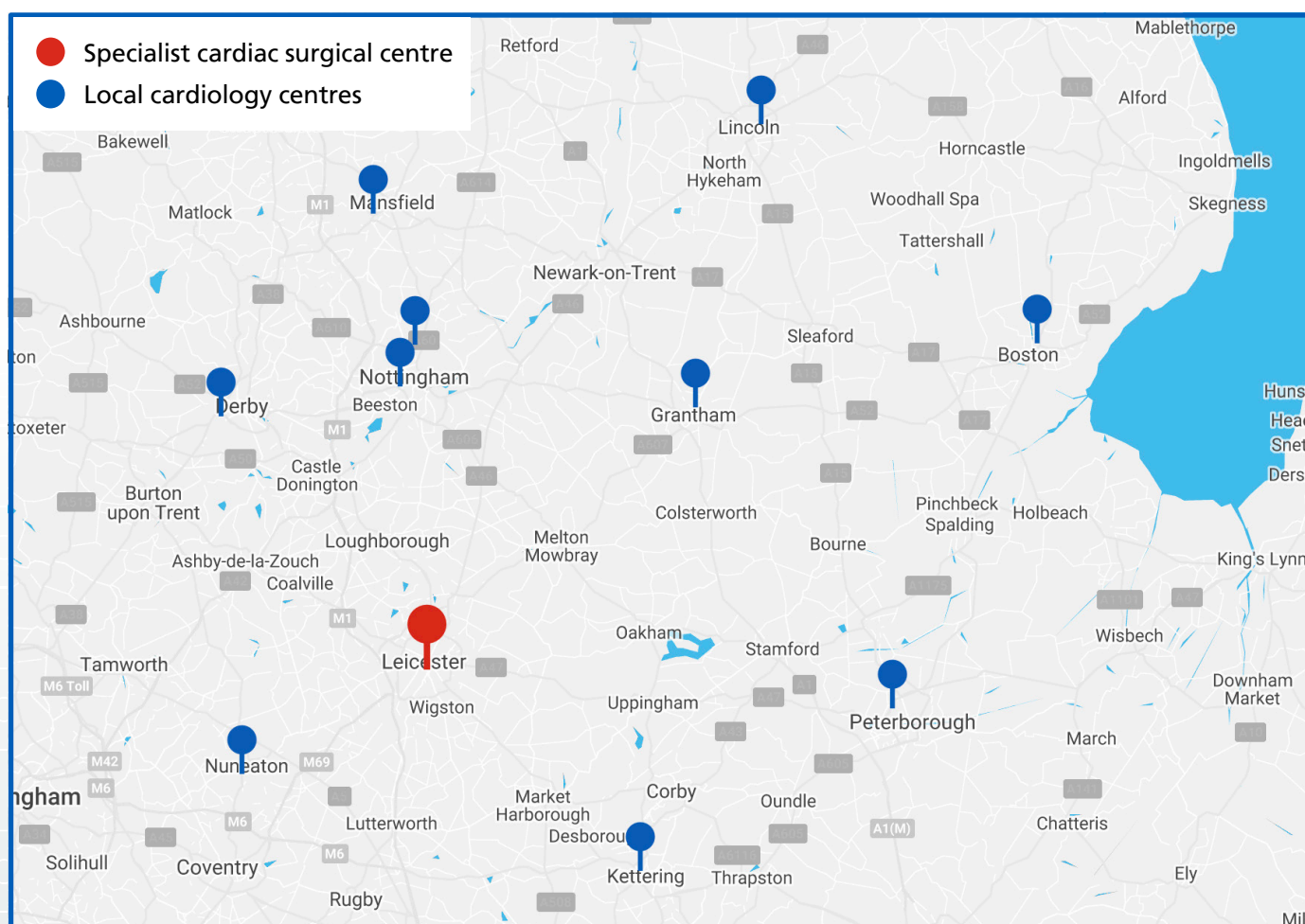
Geography

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 of **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



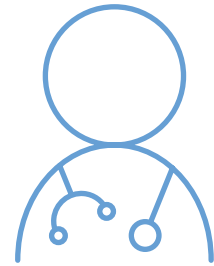
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Consultant Paediatric
Cardiologists



3

ACHD Cardiologists



10

Paediatricians with
expertise in Cardiology
(PECs)



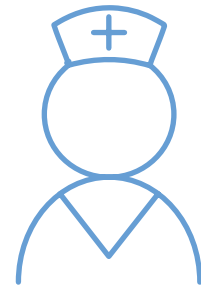
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Cardiologists with
Interest in ACHD



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

	2019-20			2020-21		
	Adult	Paediatric	Total	Adult	Paediatric	Total
Surgical Procedures	101	277	378	36	151	187
Catheter Procedures (inc Eps & Hybrids)	81	157	238	28	83	111



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.

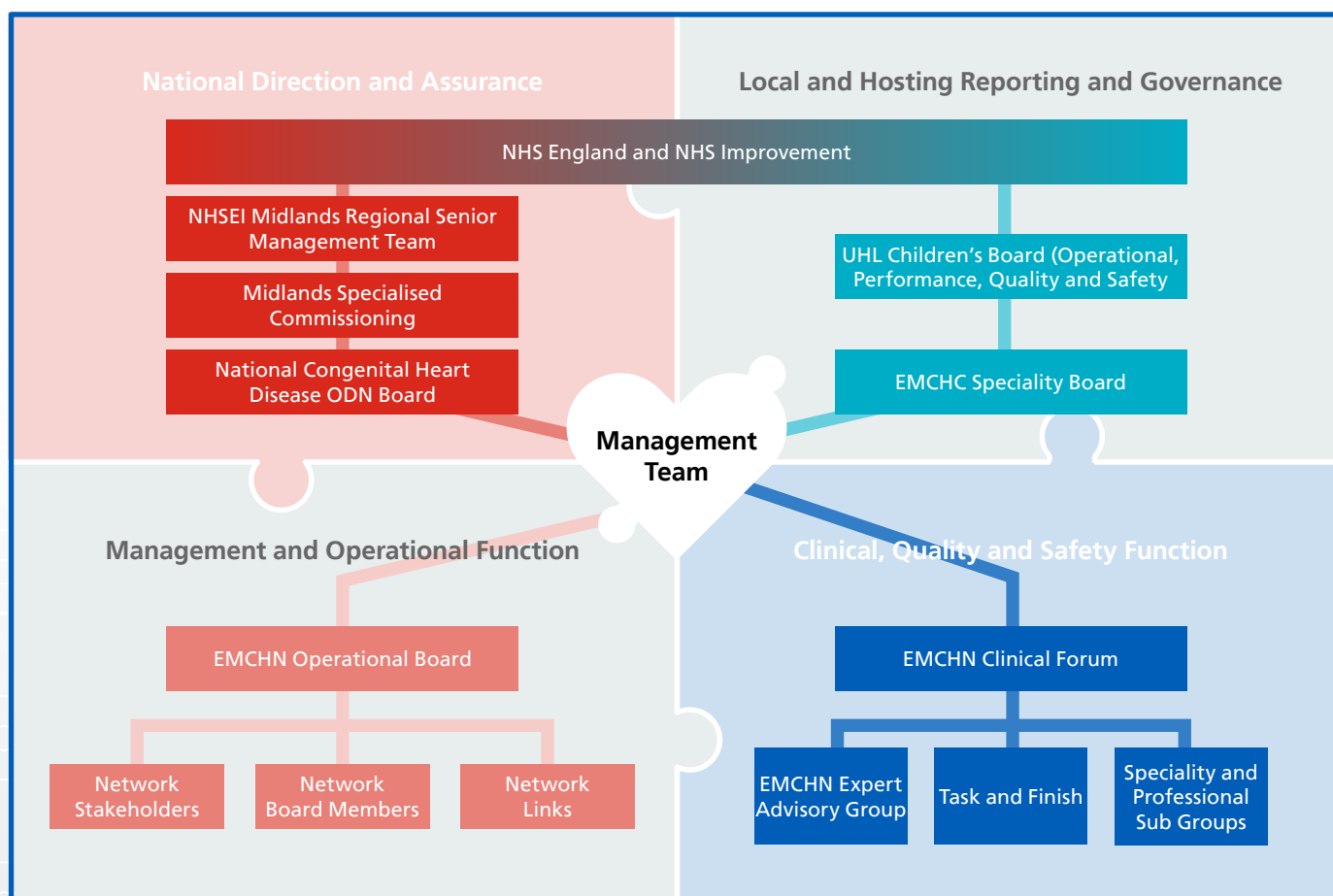
East Midlands Operational Network Board

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	£58,955
Network Nurse	8a	1	£58,955
Network Administrator	5	1	£35,448
Consultant time		2 sessions	£13,964

Total Staffing Costs **£167,322**

Travel **£14,060**

Total Direct Costs **£181,382**

Overheads (10%) **£18,138**

Total Cost **£199,520**



2020-21 Network Highlights

East Midlands Congenital Heart Centre Site Relocation

The journey continues to relocate the children's component of the East Midlands Congenital Heart Centre to the new Children's Hospital development at the Leicester Royal Infirmary site. With building and installation work powering ahead the ambition is to be fully moved by early August 2021.

This exciting move forms part of a wider service development approach within the University Hospitals of Leicester NHS Trust. Part of this first phase brings cardiac paediatric services together on a new single-site Children's Hospital.

This development will enable a seamless approach to all aspects of paediatric cardiac care, delivered within the best possible environment for our patients and their families. The new location of services will co-locate East Midlands Children's cardiac services with the rest of paediatric specialities which has significant mutual benefits and also conforms with NHS England Service standards.

Network Communication Developments

Rebranding and Publication Pack

The new EMCHN logo and publication resource has now been developed for use across the Network. The new design aims to provide an inclusive network identity which will allow for a consistent approach to documents and resources.

Website development

The structure and design of the new EMCHN website continues to be developed and refined. The site aims to allow both ease of access to specific patient journey information for service users, and a direct resource for clinicians across the region.

Twitter launch

We are now live on twitter! The account is managed by the network management team with planned weekly tweets and real time promotion of key information and resource signposting. [@EMCHNetwork](https://twitter.com/EMCHNetwork)



Nursing update

In what has been another extraordinary year, the network had to change its work plan to focus on what could be done to assist the local, regional and national response to the Covid-19 pandemic.

Thankfully, as a network we were able to support the continuation of the majority of CHD services throughout this difficult year, with a range of adapted and mutual aid models of care.

Outreach clinics were triaged throughout the Network and continued either face to face or via telephone. We have continued to monitor backlogs and waiting lists as we embark on restoration and recovery plans.

Whilst cardiac intensive care capacity was limited regionally we were able to gain mutual aid from the Birmingham region to support our patients who required urgent intervention.

Within our Level 1 centre, the Cardiac PICU at Glenfield Hospital was utilised to assist with the significant demand on the Adult Intensive Care Provision for Covid patients and to support patients requiring Extra Corporeal Membrane Oxygenation (ECMO).

We thank all the nurses, doctors and AHP's who contributed in any way to support services during the pandemic.

Education & Training

Over the last year we have held a number of educational activities across the network. We have utilised virtual communication platforms as much as possible in order to continue delivering much of our core network educational activities.

- Collaborative education sessions delivered by Network CHD Lead Nurses (East Midlands contributing to sessions) to a national audience with over 140 delegates attending
- Weekly collaborative Multi-disciplinary meetings sessions (with inclusion of all Network PEC's)
- Lunchtime "topic of the month" education sessions to nurses throughout the Network
- Support for nurses throughout the Network to attend 6 full day "Introduction to CHD" courses.



Specialist Nurses

There has been successful recruitment of further paediatric cardiac nurse specialists and adult CHD specialist nurses to our Network. Our teams have received an unprecedented high number of telephone and email enquiries from parents and their families with concerns about their heart condition, shielding, school and work and vaccination. Guidance and support have been added to existing EMCHC websites signposting all current advice.

We have visited a number of our Network hospitals throughout the last year, meeting clinicians, stakeholders and patients. It has been useful to find out what works well in some centres and where quality improvements can be made. This is helping to inform our work plans and focus our attentions as they are needed. We will continue to visit all network hospitals as we embark on the Network Standards Review process over the coming year.

Network Psychology Update

We continue to be busy with referrals from clinicians, including some from network clinicians. We are working with the EMCHN clinical team to think about how we can utilise the website to provide relevant information and support to families across the network. This will include videos that we are hoping to have produced early in the new year, as well as centralising some existing resources on the website. This will include the EMCHN Psychology referral form, and you can also always ring us to speak about any concerns you have about a child or family, in relation to a possible referral.

We have been running the neurodevelopmental outreach project, inviting children and families to get in touch with the psychology service if they have concerns about their child's behaviour or development at key stages of development. We will be reporting back on the results of this project in due course and will continue to think about how we can identify the children and families at greatest need of our support.

We continue to build links and gain familiarity with local services across the network. This is particularly important when children's and young people's needs may not fit solely under our remit, and will be on-going work as services evolve.



Seven Key Objectives for 2021-22

Objective 1

To provide strategic direction for CHD care across the East Midlands

- Redefine Network Operational Board terms of reference and membership
- Signed MOU from each Network Trust committing to working with the Network Lead centre to meet the standards, develop workforce and identifying service risks and equipment issues
- Identify and build relationships across the region to develop appropriate service pathways and additional shared care models.

Objective 2

To monitor and drive improvements in quality of care

- Complete a full CHD standards of care review across each network centre
- Establish a network data quality dashboard to demonstrate equity of care across the network (waiting times for outpatients, time from referral to surgery, loss to transition)
- Agree and implement a risk and incident reporting process, sharing learning through Board and clinical meetings.

Objective 3

To support the delivery of equitable, timely access for patients

- Publish all clinical guidance and referral pathways on EMCHN website and promote/monitor uptake
- Encourage Network centres to remotely access MDT meetings to review referrals and participate in the treatment plan
- Support the Network centres when issues and inequalities are identified in order to help resolution.

Objective 4

To support improvements in patient and family experience

- Develop PPI strategy which includes representation on the network operational board and patient and stakeholders engagement sessions
- Utilise the EMCHN website as a single resource to provide patient information
- Develop and promote a patient user survey.



Objective 5

To support the education, training and development of the workforce within the Network

- Establish Training and education needs for all clinical professionals
- Develop network educational resources
- Offer specific CHD external training opportunities across the network

Objective 6

To be a central point of information and communication for Network stakeholders

- Fully populate and promote the new EMCHN website
- Reinstate the 'Network Echo' newsletter
- Utilise the twitter platform to raise awareness and highlight key information

Objective 7

To demonstrate the value of the Network and its activities

- Assess delivery of the network against the NHSE/I Contractual agreements
- Establish a benchmark of standards compliance
- Ensure that the network programme of work is outcome and benefits driven



Contact us

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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)

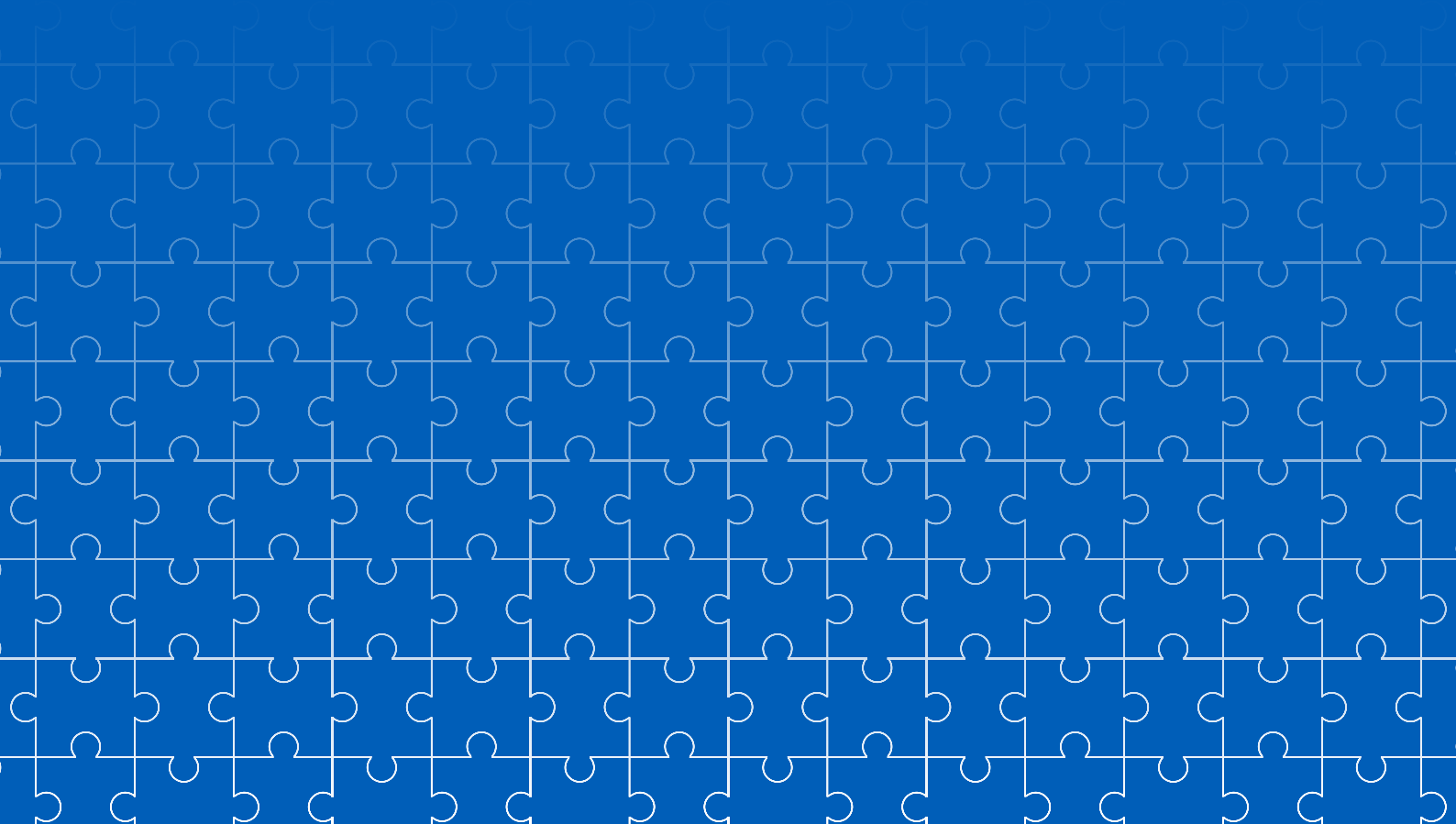
Local children's cardiology centres mainly sited in (District General Hospitals) will employ a paediatrician with expertise in cardiology (PEC) to provide ongoing monitoring and care. They will run outpatient clinics alongside specialists from the Specialist Surgical Centre. This will mean that more 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

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





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