

## NENC CHD Network – 3 year strategy

The North East and North Cumbria Congenital Heart Disease (CHD) Network management team was formerly established in January 2020. The key priorities and work of the Network team is determined by the Network Board which has representation from all 8 Trusts from across the North East and North Cumbria.

The Network covers a population of 2.9 million people in the North East and North Cumbria and is hosted by the Newcastle upon Tyne Hospitals NHS Trust.

Our vision is 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.

Our six key objectives are:

1. Increase patient and stakeholder engagement to improve inclusivity and listening.
2. Ensure equitable and lifelong access to holistic services for all CHD patients.
3. Provide strategic direction for high-quality care throughout the CHD network.
4. Promote inclusive and innovative CHD research initiatives.
5. Enhance "global" collaboration to increase the CHD network's impact.
6. Support ongoing workforce education and training, increasing general awareness.

### **Headlines for this new strategy?**

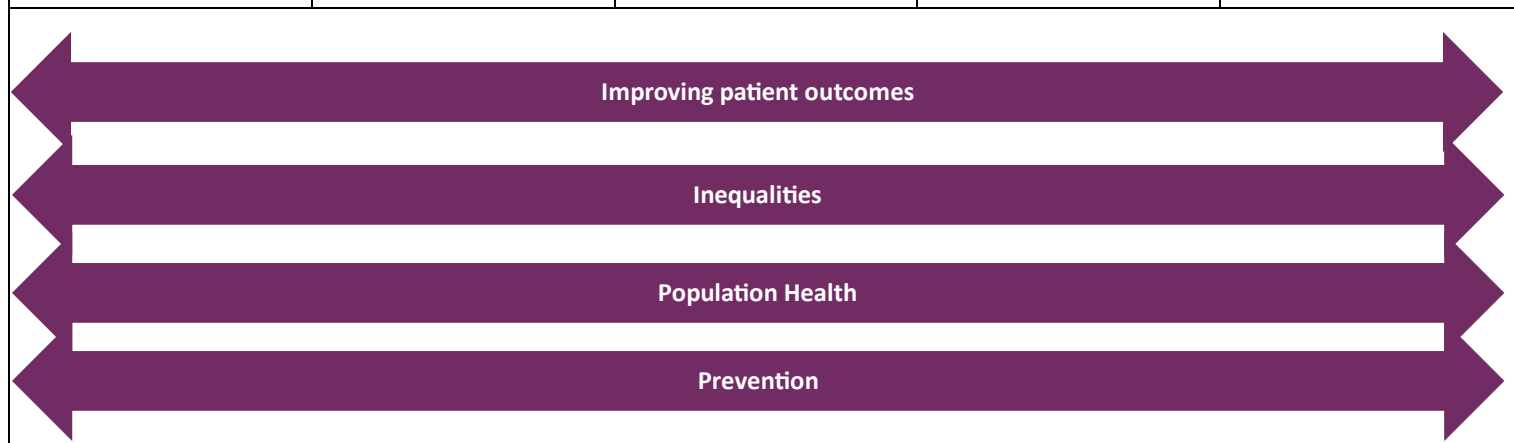
The key theme for this strategy is greater collaboration and integration between stakeholders across the geography of this CHD network.

Together with a drive for skills development, training, and a focus on innovative research, will steer us towards a more sustainable, high-quality service for congenital heart patients and their families in the North East and North Cumbria.

## The Network's 3-year strategy

The high-level objectives outlined below will be translated in to deliverable annual work plans.

objective	fetal	neonatal	children	adults
<b>1.</b> Increase patient and stakeholder engagement to improve inclusivity and listening.	Develop parent and family feedback mechanisms for fetal medicine and fetal cardiology services.	Review and improve communication with families in the antenatal period.	Develop comprehensive referral guidelines, pathways and follow-up protocols for PEC and joint clinics.	Develop an on-line support group for patients. Link with national peer to peer network
<b>2.</b> Ensure equitable and lifelong access to holistic services for all CHD patients.	Develop regional guidelines and pathways.	Standardize delivery pathways for CHD babies.	Develop a consistent Network strategy for tertiary, primary to home care (eg. INR).	Establish pathways for wider aspects of care (ambulatory, personal and local care).
<b>3.</b> Provide strategic direction for high-quality care throughout the CHD network.	Develop a multi professional case review process.  Engage in joint working between fetal and paediatric services.	Undertake a neonatal CHD audit based on place and time of delivery focused on both fetal and maternal outcomes, as well as maternal CHD outcomes.	Ensure involvement of relevant healthcare professionals from across the network in JCC meetings.  Create learning opportunities and identify common themes that may influence future CHD care.	Support clinicians to present cases at JCC.  Develop an ACHD surveillance programme to implement standardised approaches (eg. Hypertension)
<b>4.</b> Promote inclusive and innovative CHD research initiatives.	Establish an audit process to identify common themes that may influence future service delivery.	Align with other Networks on research initiatives.	Support PEC involvement in research opportunities.	Develop a learning curriculum for ACHD nurses and adult cardiologists with an interest in ACHD.
<b>5.</b> Enhance collaboration to increase the CHD network's impact.	Explore use of telemedicine for immediate CHD advice on 20 week scans.	Engage in joint working with other Networks to prioritise access for CHD babies.	Ensure timely communications between all stakeholders.  Promote GNCR adoption with stakeholders.	Investigate better engagement and collaboration with Primary Care.
<b>6.</b> Support ongoing workforce education and training, increasing general awareness.	Deliver targeted training for obstetric sonographers.	Develop guidelines for CHD place of delivery.  Develop guidelines to streamline multiple outpatient appointments.	Promote and support the Link Nurse role to be the focus point for education and communication.	Develop Top Tips for patients to help them get the most out of their follow-up consultations.



## Indicators and measures

The Network will monitor progress against the strategy by turning the priorities and indicators into items of work which will be added to the annual work plan for the network. Progress with these will be reported to NHS England and the Network board each quarter.

### Priorities and timelines

Objectives	Indicators	Measurement Methods
1. Increase patient and stakeholder engagement to improve inclusivity and listening	Patient feedback from across the network highlighting progress in the areas of our objectives and in the areas important to our patient group, positive and negative feedback heard and acted upon	Regular patient surveys and feedback mechanisms, patient involvement in network meetings and events, stakeholder engagement activities
2. Ensure equitable and lifelong access to holistic services for all CHD patients	More equitable care for all patients, no matter where they live or the complexity of their condition; high quality care with good patient outcomes	Audit and benchmarking exercises, regular review of protocols and pathways, outreach clinics and telemedicine services, collaboration with other networks and providers
3. Provide strategic direction for high-quality care throughout the CHD network	Improvement in patient outcomes and the support offered to patients and families is impactful on the quality of their lives, improvement and innovation continues; knowledge of all work being done Network Annual reports having more and more data and input outside the surgical centre and reports; clear development in the areas above	Regular network review and planning meetings, monitoring of key performance indicators, annual reports and progress updates, stakeholder feedback and consultation
4. Promote inclusive and innovative CHD research initiatives	Positive patient and family feedback, good staff morale and well-being, improved clinical outcomes and patient feedback	Collaboration with academic and research institutions, funding and support for research initiatives, regular review of research outputs and impact
5. Enhance and expand collaboration to increase the CHD network's impact	Tertiary centre confident that referrals are appropriate and timely and that pathways for care are established; paediatricians in cardiology feeling well supported, access to CPD activity for PECs; link nurses established in the region	Collaboration with other networks and providers, participation in international conferences and working groups, sharing of best practices and knowledge exchange
6. Support ongoing workforce education and training, increasing general awareness	Regular audit and review of patient satisfaction and complaints, better coverage of CHD services across the region	Professional development and training opportunities for network members, regular review of education and training programs, participation in national and international training initiatives

## Priorities for 2024/25

### FETAL

- Develop a multi professional case review process.
- Engage in joint working between fetal and paediatric services.

### NEONATAL

- Undertake a neonatal CHD audit based on place and time of delivery focused on both fetal and maternal outcomes, as well as maternal CHD outcomes.

### PAEDIATRIC

- Develop comprehensive referral guidelines, pathways and follow-up protocols for PEC and joint clinics.
- Ensure involvement of relevant healthcare professionals from across the network in JCC meetings.
- Create learning opportunities and identify common themes that may influence future CHD care.

### ADULT

- Establish pathways for wider aspects of care (ambulatory, personal and local care).
- Support clinicians to present cases at JCC.
- Develop an ACHD surveillance programme to implement standardised approaches (eg. Hypertension)