



The network listens and acts on YOUR views!

[The North East and North Cumbria Congenital Heart Disease Network \(NENC CHDN\)](#) brings together all services that deliver care across the whole life course of congenital heart disease, including prenatal diagnosis, maternity, obstetric and neonatal services, children's services, transition, adult congenital cardiac services and palliative care; providing a single collaborative network for both children and adults.

Our primary aim as a network is to work with all clinicians, commissioners, patients, parent representatives, and other stakeholders to meet the NHS England Standards. Whilst there is a small team coordinating the Northern regional network, our success is dependent on the commitment and energy of all those involved with CHD services across the region.

The term 'patients and parents' includes everyone who uses the service or may do so in the future, including carers and families. We recognise and value that the contribution of those who use the CHD services in shaping the future health care provision in our region across the organisations. Participation can take place in a variety of ways, for example email surveys, social media, attendance at meetings and working groups, representing at board meetings and national meetings. We aim to have patient and family representation from a variety of subgroups across the patient population.

The role of the patient/parent expert is to participate in discussions, critique relevant information and documentation, and champion the voice of service users across the CHD network. The aim of the patient and family engagement group will be to provide a balanced view of CHD services, both positive and negative as an expert patient or parent representative.

Your views should inform service development; this helps us get services right for patients and supports continuous improvement across the North East and North Cumbria region.

If you would like to be a part of the patient and family engagement group and contribute to forums and future developments of the congenital heart disease network, please get in touch on the contact details below!

nenc-chdn.uk

nuth.enquiries-nencchdn@nhs.net

0191 213 7504

Network Manager: Terry Phillips terry.phillips1@nhs.net

Lead Nurse: Kaye Walsh kaye.walsh1@nhs.net

Network Administrator: Rebecka Nordstrom rebecka.nordstrom@nhs.net

