



The Leeds
Teaching Hospitals
NHS Trust

Yorkshire and Humber Congenital Heart Disease Network

Standard Operational Policy



Yorkshire & Humber
**Congenital Heart
Disease Network**

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ii Information Reader Box

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iii Table of Contents

I	DOCUMENT CONTROL.....
II	INFORMATION READER BOX
III	TABLE OF CONTENTS
1	INTRODUCTION
2	NETWORK PARTNERS
3	THE NETWORK TEAM
4	NETWORK CLINICAL SERVICES AND PATHWAYS
5	NETWORK COMMUNICATION
6	NETWORK GOVERNANCE
7	NETWORK RESEARCH STRATEGY
8	NETWORK TRAINING and EDUCATION POLICY

Appendices

Appendix 1	YHCHDN Memorandum of Understanding
Appendix 2	Fetal Medicine/CHD/Genetics MDT meeting minutes
Appendix 3	Fetal Cardiology Referral Guidelines
Appendix 3a	Referral Guidelines for Fetal Echocardiology
Appendix 3b	Electronic Referral Form
Appendix 3c	Place of Delivery Pathway
Appendix 3d	Antenatal Detection Rates Audit 2018
Appendix 4	Paediatric Referral Guidelines
Appendix 4a	Referral guidelines for Paediatric Cardiology Outpatient Clinics
Appendix 4b	Referral pathway for elective cardiac surgery

Appendix 4c	Referral pathway for elective catheter intervention and diagnostic procedures
Appendix 4d	Referral pathway for elective cardiac electrophysiology or pacing procedures
Appendix 4e	Urgent referral for management of Patent Ductus Arteriosus with JQ
Appendix 4f	Referral pathway for emergency balloon atrial septostomy and temporary pacing outside of L1 provider
Appendix 4g	Referral guideline for 24/7 pre operative risk assessment for patients requiring anaesthesia
Appendix 4h	Management of patients who refer out of hours
Appendix 4i	Access to 2nd opinions and referral to other centres
Appendix 4j	Collaboration and joint working arrangements
Appendix 4k	Referral to advanced heart failure and transplant services (GOSH and Newcastle)
Appendix 4l	Referral to national pulmonary hypertension service (GOSH)
Appendix 4m	Network access to cross-sectional imaging
Appendix 4n	Arrangements for urgent dental assessments for CHD
Appendix 4o	SOP for dental screen pre surgery/intervention
Appendix 4p	SOP for initial assessment with specialist dentist
Appendix 4q	Bereavement care pathway following the death of a child
Appendix 5	Embrace Transport Service Guidelines
Appendix 5a	Preparing a neonatal patient for emergency transfer
Appendix 5b	Preparing a paediatric patient for emergency transfer
Appendix 5c	Preparing a patient for a time critical one-way transfer
Appendix 5d	Planned transfer booking form
Appendix 6	Role profile for CHD Network Link Nurses
Appendix 7	Transition pathway
Appendix 8	Network approach to minimising loss to follow up
Appendix 9	ACHD Referral Guidelines
Appendix 9a	Elective referral for cardiac surgery
Appendix 9b	Referral pathway for elective catheter intervention and diagnostic procedures
Appendix 9c	Referral pathway for elective cardiac electrophysiology or pacing procedures
Appendix 9d	Referral guideline for 24/7 pre operative risk assessment for patients requiring anaesthesia
Appendix 9e	Management of patients who refer out of hours
Appendix 9f	Access to 2nd opinions and referral to other centres
Appendix 9g	Retrieval, transfer and repatriation arrangements with suspected CHD
Appendix 9h	Pregnancy and contraception pathway
Appendix 9i	In utero transfer policy (Embrace)

Appendix 9j	Referral to advanced heart failure and transplant services (Newcastle)
Appendix 9k	Referral to national pulmonary hypertension service (Sheffield)
Appendix 9l	Network access to cross-sectional imaging
Appendix 9m	Arrangements for urgent dental assessments for CHD
Appendix 10	List of Specialist Dental Practitioners
Appendix 11	Agendas and attendance lists from Network Clinical meetings
Appendix 12	YHCHDN Annual Report 2017-18
Appendix 13	Notes from Patient and Parent Reference Group
Appendix 14	YHCHDN Terms of Reference
Appendix 15	Network Board current membership
Appendix 16	Agendas and Notes from Network Board
Appendix 17	Network Risk Management Policy
Appendix 18	Network Risk Register
Appendix 19	Network Business Meetings
Appendix 20	Quarterly Dashboard Report proforma
Appendix 21	Network Quarterly Dashboard Report Oct-Dec 2018
Appendix 22	YHCHDN Clinical Guidelines policy
Appendix 23	Minutes from Quarterly meeting with NHSE Yorkshire and Humber
Appendix 24	YHCHDN Incident Reporting Tool
Appendix 25	Specialist Services Quality Dashboard
Appendix 26	Work Programme 2018-19
Appendix 27	Network Research Strategy
Appendix 28	Network Training Policy
Appendix 29	Nurse Education Training Strategy
SSC1888	Network Deliverables

1. Introduction

- The Yorkshire and Humber Congenital Heart Disease Network (YHCHDN) covers a population of 5.6 million people in Yorkshire, the Humber and North Derbyshire.
- The Network was re-launched as an integrated Network in January 2018, in line with the requirements of NHS England’s Congenital Heart Disease (CHD) Standards and Specifications (2016), building on a long history of hub and spoke service provision and clinical networking.
- Our vision is to be a Network where our patients have access to the highest quality CHD care, irrespective of age or where they live. We want to provide care as close to home as possible, but also to ensure a seamless transition between services and locations. We aim to listen to and respect what patients and their families tell us is important to them and adapt our services accordingly. We are committed to collaborative working and continual service improvement.

2. Network Partners

The Network comprises

- **Host Provider**
Leeds Teaching Hospital Trust (LTHT)
- **Specialist Commissioning Organisation**
Yorkshire and Humber NHSE
- **Level 1 Specialist Children’s Surgical Centre**
Leeds Teaching Hospitals Trust (Leeds Children’s Hospital)
- **Level 1 Specialist ACHD Surgical Centre**
Leeds Teaching Hospitals Trust (Leeds General Infirmary)
- **Referring hospitals for children’s CHD services**
Airedale General Hospital (Level 3 Local Cardiology Centre)
Barnsley Hospital (Level 3 Local Cardiology Centre)
Bradford Teaching Hospitals (Level 3 Local Cardiology Centre)
Calderdale Royal Hospital (Level 3 Local Cardiology Centre)
Chesterfield Royal Hospital (Level 3 Local Cardiology Centre)
Dewsbury District Hospital (Level 3 Local Cardiology Centre)
Diana Princess of Wales Hospital, Grimsby (Level 3 Local Cardiology Centre)
Doncaster and Bassetlaw Teaching Hospitals (Level 3 Local Cardiology Centre)
Harrogate District Hospital

Hull Royal Infirmary (Level 3 Local Cardiology Centre)
Pinderfields General Hospital (Level 3 Local Cardiology Centre)

Rotherham General Hospital (Level 3 Local Cardiology Centre)
Scarborough General Hospital (Level 3 Local Cardiology Centre)
Scunthorpe General Hospital (Level 3 Local Cardiology Centre)
Sheffield Children's Hospital (Level 3 Local Cardiology Centre)
York District Hospital (Level 3 Local Cardiology Centre)

○ **Referring hospitals for ACHD services**

Airedale General Hospital
Barnsley Hospital
Bradford Teaching Hospitals
Calderdale Royal Hospital
Castle Hill Hospital, Hull (Level 3 Local Cardiology Centre)
Chesterfield Royal Hospital
Dewsbury District Hospital
Diana Princess of Wales Hospital, Grimsby
Doncaster and Bassetlaw Teaching Hospitals
Harrogate District Hospital
Hull Royal Infirmary
Pinderfields General Hospital
Rotherham General Hospital
Scarborough General Hospital
Scunthorpe General Hospital
Sheffield Teaching Hospitals (Level 3 Local Cardiology Centre)
York District Hospital

○ **Fetal Medicine Units**

Leeds Teaching Hospitals
Sheffield Teaching Hospitals (Jessop Wing Maternity Unit)

○ **Maternity/Neonatal Units**

Airedale General Hospital (Level 2 Local Neonatal Unit)
Barnsley Hospital (Level 2 Local Neonatal Unit)
Bassetlaw Hospital (Level 1 Special Care Baby Unit)
Bradford Teaching Hospitals (Level 3 Neonatal ICU)
Calderdale Royal Hospital (Level 2 Local Neonatal Unit)
Chesterfield Royal Hospital 2 (Level 2 Local Neonatal Unit)
Diana Princess of Wales Hospital, Grimsby (Level 2 Local Neonatal Unit)
Doncaster Hospital (Level 2 Local Neonatal Unit)
Harrogate District Hospital (Level 1 Special Care Baby Unit)
Hull Royal Infirmary (Level 3 Neonatal ICU)
Jessop Wing, Sheffield (Level 3 Neonatal ICU)

- Leeds Teaching Hospitals (combined) (Level 3 Neonatal ICU)
- Pinderfields General Hospital (Level 2 Local Neonatal Unit)
- Rotherham General Hospital (Level 2 Local Neonatal Unit)
- Scarborough General Hospital (Level 1 Special Care Baby Unit)
- Scunthorpe General Hospital (Level 2 Local Neonatal Unit)
- Sheffield Children's Hospital (Level 3 Neonatal Surgical Unit)
- York District Hospital 2 (Level 2 Local Neonatal Unit)
- **Paediatric Intensive Care Units (PICU)**
 - Leeds Teaching Hospitals (Leeds Children's Hospital)
 - Sheffield Children's Hospital
- **Transplant Providers**
 - Great Ormond Street Hospital (Children)
 - The Freeman Hospital, Newcastle (Children and Adults)
 - Royal Papworth Hospital (Adu)
- **Pulmonary Hypertension Provider**
 - Sheffield Teaching Hospitals (ACHD)
 - Great Ormond St Hospital (Children's CHD)
- **Affiliated Academic Institutions**
 - University of Leeds
 - Leeds Beckett University
 - Hull York Medical School
 - University of Bradford
 - University of Sheffield
- **Local Charity Support**
 - Children's Heart Surgery Fund

The roles and responsibilities of the different partner organisations are described in the YHCHDN Memorandum of Understanding (Appendix 1).

3. The Network Team

- **Network Lead Clinician**

The Network Lead Clinician is Dr Elspeth Brown who is a Paediatric Cardiologist based at Leeds Teaching Hospital Trust. Dr Brown was appointed in March 2017 and has an allocation of 2 PAs in her job plan for the Network Lead Clinician role.
- **Network Lead Nurse**

The Network Lead Nurse is Jo Quirk who has worked as a Specialist Nurse in both children's CHD services and ACHD services. Jo was appointed in January 2018 and provides 30 hours per week to the Network Lead Nurse role.
- **Network General Manager**

The Network General Manager is Debra Wheeler who has occupied a number of General Manager posts within Leeds Teaching Hospitals. Debra was appointed on a full time basis in July 2018 to establish the Y+H CHD Network and from May 2019 she will provide 22.5 hours per week to the Network General Manager role.

○ **Network Administrator**

The Network Administrator is Mireia Moriel who provides 7.5 hours per week to the role. Mireia is currently on maternity leave.

○ **Specialty Lead ACHD**

The Specialty Lead for ACHD is Dr Kate English. Kate is a Consultant ACHD Cardiologist at Leeds Teaching Hospitals and has 1 PA allocated to the role.

○ **Specialty Lead CHD Anaesthesia**

This role is split between Dr Jutta Scheffczik and Dr Mike Cross. Jutta is a Consultant Paediatric Anaesthetist and Mike is a Consultant Cardiac Anaesthetist. They both have 0.25 PAs allocated to the role.

4. Network clinical services and pathways

○ **Specialist Surgical Centre for Children's CHD and ACHD Services**

- The Network is distinguished by the fact that its Specialist Surgical Centre for both children's and adults are co-located at Leeds General Infirmary, alongside fetal cardiology, maternity services, neonatal services, all children's services and a wide range of adult services.
- These co-locations meet all of the requirements of the national service standards and specifications and enable patients and families to receive all of their specialist care under one roof.
- A weekly MDT meeting (paediatrics and ACHD combined) is held in the Specialist Surgical Centre in Leeds every Tuesday morning.

○ **Fetal Cardiology Pathways**

- The Fetal Cardiology Department is physically located adjacent to the Fetal Medicine Department in Leeds General Infirmary enabling excellent clinical communication between Fetal Cardiology and Fetal Medicine clinical staff.
- There is a weekly MDT meeting with representatives from Fetal Medicine, Fetal Cardiology, Neonates and Genetics and a copy of minutes from a recent meeting are attached at Appendix 2.
- Clinics operate 5 days per week with support available to all patients from a fetal cardiac nurse specialist on the day of diagnosis. Routinely over 90% of patients with a suspected antenatal diagnosis of CHD are being seen for fetal echocardiography within 3 days.

- Referral protocols are in place across the Network and these are attached at Appendix 3.
- There are 4 Children’s hospices within the Network, providing palliative care for children with complex CHD and bereavement support for families. There is a Perinatal Care Midwife based at Forgot-me-Not Hospice in Huddersfield offering support for families following antenatal diagnosis of complex congenital heart disease. Referrals are accepted following antenatal diagnosis to support decision making and on-going family centred support is offered in parallel with the specialist team. This may include respite care, sibling support and bereavement counselling.
- Antenatal diagnosis rates are audited on an annual basis using the NICOR data definitions. The detection rates in 2018 across the Network were 56.5%. The most recent audit is attached at Appendix 3d.
- A Network multidisciplinary Fetal Cardiology Study Day is held on an annual basis to support continuing professional development, skills training and communication.

○ **Paediatric Referral Pathways**

- All specialist surgery and interventional catheterisations are carried out in the Specialist Children’s Surgical Centre in Leeds Children’s Hospital, which is part of Leeds General Infirmary.
- However the Network is committed to providing care as close to home as possible for all children with CHD, and many children receive their outpatient care, and elements of inpatient care locally.
- Consultant Paediatric Cardiologists from Leeds work closely with Consultant Paediatricians with Expertise in Cardiology (PECs) to deliver joint outpatient clinics in the 14 Local Cardiology Centres across the Network and to support them in the management of inpatients and with their continuing professional development. There are currently 19 Paediatricians with Expertise in Cardiology (PECs) working across the 14 Local Children’s Cardiology Centres in the Network
- Joint referral, care protocols and guidelines have been developed for emergency, acute and routine presentations by children with a confirmed or suspected diagnosis of CHD, and these are attached at Appendix 4.
- Emergency transfers for critically ill neonates and children are supported by the Regional Transport Service (Embrace) and their key guidelines are attached at Appendix 5.
- The role of Link CHD Nurses within the Local Cardiology Centres and Community Paediatric Services is being developed across the Network to

support the PECs, to improve communication with the Specialist Surgical Centre and facilitate the education of other staff within their area of work. More than 60 Link Nurses have now been identified and their role profile is attached at Appendix 6.

- A Network multidisciplinary Paediatric CHD Study Day is held on an annual basis to support continuing professional development, skills training and communication.
- In addition 4 Network Echocardiography Training Days are held for PECs and cardiac physiologists to maintain and develop echocardiography skills.

○ **Transition Services**

- The importance of good transition arrangements for young people requiring lifelong follow up is recognised and policies are kept under review to make this process as effective as possible and to minimise loss to follow up.
- The Network's Transition pathway is attached at Appendix 7 and the approach to reviewing and minimising loss to follow up is attached at Appendix 8.

○ **ACHD Referral Pathways**

- All specialist surgery and interventional catheterisations are carried out in the Specialist ACHD Surgical Centre at Leeds General Infirmary.
- However the Network is committed to providing care as close to home as possible for all adults with CHD, and many patients receive their outpatient care, and elements of inpatient care locally.
- Consultant ACHD Cardiologists from Leeds work closely with Adult Cardiologists with expertise in ACHD, to deliver joint outpatient clinics in the 2 Local Cardiology Centres in the Network and to support them in the management of inpatients and with their continuing professional development.
- Joint referral, care protocols and guidelines have been developed for emergency, acute and routine presentations by adults with a confirmed or suspected diagnosis of CHD and these are attached at Appendix 9.
- Cardiologists have been identified in the other hospitals within the Network, to improve communication with the Specialist Surgical Centre and facilitate the education of others within their area of work. Link ACHD Nurses are also in the process of being identified, and the role profile is attached at Appendix 6.
- A weekly MDT meeting (paediatrics and ACHD combined) is held in the Specialist Surgical Centre in Leeds every Tuesday morning.

- The first Network multidisciplinary ACHD study day is being held in May and this will be provided on an annual basis.

○ **Clinical Support Services**

Physiotherapy and psychology support are both embedded in the clinical pathways for adults and children and work closely with the wider MDT to provide support across the Network. Both services regularly provide educational input into the Network Clinical meetings and Transition Evenings.

- **Psychology**

- The team is made up of Clinical Psychologists, Counsellors and an Assistant Psychologist. The team work with patients and families to prevent and minimise psychological distress associated with their medical condition. Working closely with the wider MDT the team aims to maximise the health benefits that can be gained from the medical and surgical care.
- Particular input is provided into the Fetal Cardiology, the Neonatal Unit, Surgical Clinic, the “High Risk “clinic for children with complex hearts and single ventricle conditions, the Inherited Cardiac Conditions clinic and therapeutic outpatient sessions.
- The Team runs a Surgical Preparation Clinic supported by a Play Therapist for patients who need extra support in preparation for surgery.

- **Physiotherapy**

- Physiotherapy service is an integral part of the multidisciplinary “High Risk” pathway for infants who will follow the single ventricle pathway. Patients are assessed while an inpatient and followed up in clinic to assess their developmental milestones and to facilitate them achieving their potential. This allows advice and support with introduction of tummy time and advice on manual handling.
- Children who undergo Fontan procedures are reviewed by physiotherapy at the time of surgery and followed up as an outpatient to establish re integration into school.
- All cardiology patients can be referred to the service for advice on support on appropriate exercise and physical activity pathways throughout their journey and can be assessed at home, school and in the hospital situation.

○ **Dental Services**

- The Network has appointed a Specialty Lead for CHD Dentistry who is a member of the Network Board.
- There is excellent specialist dental practitioner coverage across the Network, and a list of current practitioners is attached at Appendix 10.
- **Palliative Care and Bereavement Services**
 - There are 4 children’s hospices and 16 adult hospices in the Network, working in parallel with the specialist congenital heart disease teams and Local Cardiology Centres offering support, respite care and bereavement counselling to patients and their families
 - A bereavement pathway for the Network following the death of a child has been developed and is attached at Appendix 4k.

5. Network communication

- **Telemedicine**
 - The Network is committed to providing a telemedicine facility to link all the designated Centres across the Network to improve the timeliness of clinical decision making and to support education and training.
 - A system is currently being trialled in one of the Local Cardiology Centres which enables remote assessment of echocardiograms, discussion of emergency referrals, transfer and receipt of images, and participation in MDT meetings and other educational meetings. This will be evaluated over the next 6 months and if the system delivers as expected a business case will be developed to roll this out across the Network.
- **Remote viewing of echocardiograms**
The national Image Exchange Portal (IEP) is used for remote viewing of echocardiograms for clinical opinion, discussion at MDT and referral to other Centres outside of the Network.
- **Review of cross- sectional imaging**
Cross sectional imaging e.g. CT/MRI is reviewed on a weekly basis at the Network MDT meeting in Leeds. Images are again transferred by IEP or CD as appropriate.
- **Remote access to electronic patient records**
 - All clinical information relating to a patient’s CHD care is held on Oscar 4D, the Network clinical database. The database cannot be accessed remotely outside of Leeds, either to input information or view information. All clinical correspondence generated from the joint clinics in the Local Cardiology Centres is emailed to Leeds Teaching Hospitals and uploaded onto the Network database.

- A business case is being developed to migrate Oscar 4D into Leeds Teaching Hospitals Electronic Health Record (PPM+) which will enable remote access across the Network. The timescale for this migration is expected to be 12-18 months.
- There are a number of local and national initiatives underway to develop electronic patient held records, but no concrete timescales for implementation.

○ **Communication to Stakeholders**

The Network uses a variety of methods to communicate with its stakeholders

- **Network Website**

www.networks.nhs.uk/nhs-networks/yorkshire-and-humber-congenital-cardiac-network

This is aimed at staff working within the Network and provides information on meetings, educational events, useful documents and guidelines and procedures

- **Network Clinical Meetings**

- These meetings are held in January and June at different venues across the Network. They are aimed at all staff working within the Network and the meeting agendas cover a mixture of management and clinical issues.
- The agendas from the last two meetings are attached at Appendix 11.

- **Aligned Networks**

- There are close formal and informal working relationships in place with aligned Networks nationally and across the Yorkshire and Humber.
- At an operational level, the co-location of fetal, maternity, neonatal and intensive care facilities on the Leeds General Infirmary facilitates excellent clinical communication and multi-disciplinary team working.
- The Lead Clinician from the Network attends the Embrace Transport Delivery Group which discusses operational and strategic issues in relation to the regional transport service. One of the Embrace Consultants sits as a member of the YHCHDN Board.
- There is a Yorkshire and Humber Paediatric Networks Clinical Oversight Group which meets on a quarterly basis and brings together the Lead Clinicians from the Fetal, Maternity, Neonatal, Paediatric Intensive Care, Transport and Paediatric Neurosciences Networks in the Yorkshire and Humber. This is a recent development and the purpose of the meeting is to improve communications and

awareness of current work streams across the aligned Networks and explore opportunities for joint improvement work.

- **Annual Report**

The Network produced its first Annual Report in October 2018 and this was distributed widely across the Network. A copy is attached at Appendix 12.

- **Patient and Parent Reference Group**

- This group is open to patients and parents across the Network. It meets on a quarterly basis and provides a reserve of people to represent the patient/parent voice on the Board, to speak at meetings, to critique patient information and to work on service development issues.

- The notes from two previous meetings are attached at Appendix 13.

- **Social Media**

The Network promotes activities and educational events through its Twitter account @YHCHDN

6. Network Board

- The Network Board was established in October 2018. It meets four times per year and is chaired by Dr Sandeep Kapoor, the PEC from Scunthorpe General Hospital.
- The Board's Terms of Reference are attached at Appendix 14.
- The Board's current membership and action notes from the previous 2 meetings are attached at Appendix 15 and Appendix 16.

- **Network Governance Structure**

- The Network's formal governance structure is described in the Network Terms of Reference (Appendix 14) and the Memorandum of Understanding with its partner organisations (Appendix 1)
- The Network has a Risk Management Policy which describes the process by which risks affecting YHCHDN will be identified, managed and reviewed. A copy is attached at Appendix 17 .The Network has an active Risk Register which is reviewed on a six monthly basis by the Network Board, NHS England Yorkshire and Humber and Leeds Teaching Hospitals Trust. A copy of the current Risk Register is attached at Appendix 18.

- **Network Business Meetings**

There is a regular cycle of Network business and management meetings and these are described at Appendix 19.

○ **Performance Management**

- On a quarterly basis the Network requests each Centre to provide a Quarterly Performance Report .A copy is attached at Appendix 20.
- There will be individual Annual Review meetings with all of the Centres in the Network to review compliance against the national service standards and to discuss general capacity issues and future plans. These are scheduled to start in May.

○ **Equity of Access**

- The Board has agreed a set of referral guidelines for the paediatric outpatient clinics aimed at ensuring consistency within the PEC Clinics and the Joint Clinics. These are attached at Appendix 4a.
- Waiting times for new patients, adherence to indicated follow up intervals and WNB/DNA rates are reviewed at each Board meeting .A copy of the last Quarterly Performance Dashboard is attached at Appendix 21

○ **Agreement of Clinical Guidelines**

The Board has a Clinical Guidelines Policy, detailing how clinical guidelines should be written and the approvals process. This is attached at Appendix 22.

○ **Outcomes Monitoring**

- Outcomes at the Specialist Surgical Centre are discussed on a monthly basis at the local Clinical Governance meeting and reported to NHSE through the Specialist Services Quality Dashboards. These outcomes are discussed with the Network and NHSE Yorkshire and Humber managers at the Quarterly Quality Meeting, and a copy of the minutes from a recent meeting are attached at Appendix 23.
- In addition the Network has developed an Incident Reporting Tool as part of its Risk Management Policy to encourage stakeholders to report adverse incidents so lessons can be learned across the Network. The Incident Reporting Tool is attached at Appendix 24.

○ **Reviewing National Outputs**

- The Specialist Services Quality Dashboards allow for national comparison and benchmarking against peer Specialist Surgical Centres and these are discussed on a quarterly basis with the Network, NHSE Yorkshire and Humber managers and CHD clinical managers from Leeds Teaching Hospitals. A recent example is attached at Appendix 25.

- Feedback from the National CHD Patient Experience Survey is discussed by the Patient and Parent Reference Group and by the Network Board following release of the quarterly report.
 - In addition each Local Cardiology Centre is carrying out a Family and Friends survey of a PEC and Joint Clinic every 6 months and this forms part of the annual review meeting between the Network and the Local Cardiology Centres.
- **Annual Plan**
The annual plan for 2018-19 was developed in the Autumn as part of the review of the previous year and was heavily linked to achieving compliance with the national standards. A copy is attached at Appendix 26.

7. Network research strategy

- The Network recognises the role of research in improving outcomes and is keen to see equity of access to clinical trials across the Network.
- The Network Research Strategy is attached at Appendix 27.

8. Network training and education policy

- The Network recognises that the delivery of high quality care for children and adults with congenital heart disease depends on close multidisciplinary working between many health professionals and allied staff.
- A Network Training Policy has been developed which is attached at Appendix 28.
- A stand-alone Network Education Strategy for Nurses has been developed and this is attached at Appendix 29.