

Quality Indicators - Peer Review Report

Network Name: The Yorkshire and Humber Congenital Heart Disease Network	Date of Review: 5/6/19
Service: Adult Congenital Heart Disease – Network	Type of review: Comprehensive

Self-Declaration Compliance	87.5%	Peer review compliance	62.5%
------------------------------------	-------	-------------------------------	-------

The Yorkshire and Humber Congenital Heart Disease Network (YHCHDN) was formally re-launched in January 2018. The YHCHDN is hosted by Leeds Teaching Hospitals NHS Trust (LTHT), which is also the provider of the specialist surgical services for both paediatrics and adults. Surgery is undertaken at Leeds General Infirmary where fetal and maternity services are also co-located. The demographic profile of the 5.6 million population covered by the network, is very mixed, ranging from densely populated urban areas with significant pockets of deprivation and large immigrant populations, to sparsely populated rural communities and isolated coastal fringes. Bradford District has the largest population of people of Pakistani ethnic origin in England, bringing with its higher rates of congenital heart disease.

Structure and Process

Number	Indicator	SD Compliance	PR Compliance
101	There is a Network Management team as per SSC1888	Y	Y
Comments	The current network management team, which has been in place since March 2017 comprises of the required membership of a network clinical director, network lead nurse, network manager and an administrator. The network director has an agreed job description, including details of responsibilities, with 2 Programmed Activities (PAs) per week dedicated to their role. The lead nurse works 32 hours (0.85 whole time equivalent (WTE)) over four days per week and the network manager, who previously worked full time while establishing the network, now works three days per week. While there is an agreed budget for a full-time administrator post, the current post holder, who is on planned long term		

	<p>leave, works one day per week. The reviewers were advised that cover for the administrator is provided by the clinical support unit (CSU). There are plans to increase the number of days worked by the administrator to two days per week from September 2019.</p> <p>In addition to the management team, two speciality leads are also funded to provide support for the network; there is 1 PA per week for an adult congenital heart disease cardiologist and 1 PA per week joint for an adult and a paediatric anaesthetist.</p> <p>While the network team considered the current working time was sufficient to undertake their roles, the reviewers encourage them to consider an increase for both the network manager and lead nurse which may allow more time to develop the strategic overview of networking.</p>		
102	There is an agreement outlining the network configuration	Y	Y
Comments	<p>In 2016 a gap analysis in terms of level 1 service and network requirements was undertaken; as a result, a business case was developed which led to LTHT agreeing to fund the network for a three-year period as a cost pressure. Current funding for the network is being reviewed by NHS England with the expectation that the specialised contract with the Trust will continue until 2020/2021.</p> <p>The network has a detailed operational policy which describes the specific catchment population, the named host provider for the network, a list of all units referring patients to the Level 1 network provider, the classification of each unit in the network, and the affiliated academic institutions. It was noted the transplant services are provided by GOSH and Newcastle and referral pathways are in place. Also, the pulmonary hypertension services are overseen by GOSH for Paediatrics and Sheffield for adults with referral pathways and an SLA for shared care arrangements. During the review meeting, the network team described how the level 1 providers support to adult outreach clinics within Sheffield Teaching Hospitals NHS Foundation Trust (STHT) and Hull University Teaching Hospitals NHS Trust (HUTH). The consultant based at STHT has a long-term special interest in adult CHD service and is recognised as having considerable experience in the service (grandfather clause). The consultants based at HUTH has undertaken additional training to allow them to participate in the joint clinics. The outreach services at Sheffield and Hull were developed as the network recognised the need to provide care closer to home in the more densely populated areas of the region. Taking population needs into account, there are plans to develop a third outreach service at Bradford Teaching Hospitals NHS Foundation Trust (BTH) which should assist in reducing the number of patients lost to follow up with care closer to home, with one of the consultants locally undertaking additional training with the aim to open joint clinics from December 2019. More complex patients and those with a defined pathology will still need to attend outpatient clinic appointments at the level 1 centre in Leeds. The reviewers encourage the network to include additional details</p>		

	<p>within the operational policy to reflect the criteria for level 1 patients being offered joint clinic access as part of the outreach service.</p> <p>The reviewers commend the network for developing a memorandum of understanding which has been agreed and signed by representatives for all CHD providers within the region which ensures robust clinical engagement into network development.</p> <p>The network team described good working links with the specialised commissioning team within the Yorkshire and the Humber regional hub with quarterly meetings to discuss a range of key performance indicators and the activity within the level 1 centre. There are plans to jointly undertake a whole system review of the tariff across the network to ensure consistency between providers. There was an acknowledgement that further work needs to be undertaken to ensure consistency in the way that data is recorded across the network. Both the network team and commissioning representatives at the meeting reported the feeling of mutual support.</p> <p>The reviewers commend the network for the awareness regarding which areas of the service are to be developed. This is enhanced by the long-standing history of the network team.</p>		
103	There are networking facilities in place that enable communication across the network	N	N
Comments	<p>The network has established good communication practices across the region which were described in the operational policy.</p> <p>A telemedicine system has been established between Leeds General Infirmary and BTH to allow real time review and discussion of echo images. However, the system is limited and has been superseded by new technology. Consequently, a new telemedicine system has been purchased by the Network and this is currently being evaluated in Mid Yorkshire Hospital Trust (Pinderfields Hospital). If this meets the Network's requirements a business case will be developed to roll the system out across the Network. The aim is to provide a system which enables video conferencing and real time discussion of echos and advice between the Surgical Centre and the Local Cardiology Centres.</p> <p>Patients records are currently stored within an electronic database, Oscar 4D however, this is considered no longer fit for purpose and the network are considering migrating the information to the PPM system.</p> <p>The reviewers recognise a number of plans to ensure robust network facilities are in place across the region and encourage the network to include the developments as part of a five-year business plan with elements of the pilot programmes highlighting timed milestones and how any areas of non-compliance are going to be addressed.</p>		

104	There is a network board meeting	Y	N
Comments	<p>The operational policy lists the members of the network board and also includes terms of reference confirming the plans for meetings to be held four times per year. It was noted that the network is chaired by a Paediatrician with Expertise in Cardiology (PEC) from one of the referring units. Copies of minutes from network board meetings were available at the review. The network representatives advised that they are still at the relatively early stages of developing the network clinical governance arrangements. All stakeholders are represented at the network board meetings and communication is via the PECs and senior management teams. The reviewers consider the requirements for representatives from eight of the level 3 providers to be present at the meeting in order for them to be quorate is quite ambitious.</p> <p>The network board can enlist the support and input from other clinical areas such as maternity and neonatal services. There is a joint clinic between maternity and CHD each week with the lead obstetrician from LTHT being the maternity medicine network lead. The team also described good communication with other networks such as the neonatal, maternity and fetal networks. A number of associated services are co-located at LTHT which helps ensure good communication.</p> <p>There is a cohort of 20 PPV representatives, two of which attend the network board meetings on a rotational basis with one representing the adult service and the other the paediatric service. While the two PPV representatives at the review meeting reported that they feel well supported and able to express the views of patient's, they have not received any formal training in line with the NHS England requirements. The lead consultant clinical psychologist reported that the patient group has developed organically, but that consideration was being made to develop formal workshops. The patient representatives described good links with the children's charity, "Children's Heart Surgery Fund" and highlighted the high quality of care they receive, focusing on the family elements to provide "wrap around care".</p> <p>There are separate meetings specifically for the patient representatives for which they can set their own agenda. An example of how the patient group has been able to support the network function was demonstrated by a suggestion put forward to highlight the cost of "missed appointments" in an attempt to reduce the DNA rates; as a consequence, appointment letters and reminder texts now includes reference to the cost of patients not attending on planned dates.</p> <p>The reviewers commend the network for the comprehensive structure below the board level which supports service improvement.</p> <p>There are plans to hold an extended board "time out" event in September 2019 for patients/parents, nurses, echocardiographers, neonatal and maternity staff to help understand future plans for engagement. The network is also looking at network issues which may impact on the quality of care being provided; these include a look at DNA rates across the region, monitor the capacity and demand, fetal diagnosis rates, and how and when patient follow up is</p>		

	undertaken. However, the network team has not yet developed and reviewed a five-year plan regarding service development. There are some shorter-term action plans, but the reviewers encourage the team to develop a longer term strategic plan and to extend operational plans to reflect some of the work being undertaken in terms of benchmarking and improving the network facilities.		
105	There are network agreed patient pathways	Y	N
Comments	<p>Documentation provided for the external peer review visit confirmed that there are patient pathways as listed in SSC1888. However, it was noted that not all pathways had been through a formal governance process for agreement by the network group. Some were merely a description of the pathways followed and had not been approved by the Board, in addition review dates and processes were not recorded. The reviewers encourage the network to formally agree all pathways to ensure a robust governance process is implemented.</p> <p>The reviewers commend the comprehensive guidelines for the joint care of patients delivered by the anaesthetic and dentistry teams to ensure that all patients have a dental check-up prior to surgery. Information cards have been developed to provide information about the importance of dental hygiene and the prevention of endocarditis and have been distributed across the region.</p>		
106	There is a network agreed research strategy including access and participation in clinical trials	Y	Y
Comments	<p>Evidence provided to the reviewers confirmed a comprehensive range of clinical research is being undertaken by the level 1 providers. The network acknowledge that the majority of the research work is being undertaken at the level 1 centre and as a result it is important to ensure that there is an equity of access to research and clinical trials for all patients within the region. The network is currently undertaking a piece of work looking at the effect of where patients are seen and by whom, in relation to participation in research.</p> <p>The network has also recently looked at the population of the various level 3 units. The information obtained is being utilised to target education of staff to ensure an equity of access for patients.</p>		
107	There is a network agreed policy in relation to training	Y	Y

<p>Comments</p>	<p>The network is to be commended on the levels of training supported throughout the region and across different disciplines involved with the care of CHD patients.</p> <p>While there is good attendance at the study days, the network team acknowledged the difficulties in the release of staff from hard pressed clinical areas and have invested significantly in Link Nurses. The lead nurse for the network has identified an individual within each of the level 3 hospitals who act as the link nurse. The link nurses are then encouraged to attend the training days and cascade the training to local nursing teams.</p> <p>An educational event was held in October 2018 for all link nurses within the region and as a result there is now a shared e-mail system established to promote communication network-wide. There has also been an adult CHD education training event held in May 2019 whereby 55 staff attended across the region including nurses, cardiologists and physiologists.</p> <p>The neonatal nursing team recognised a gap in their knowledge and as a result developed a folder with guidelines and policies for the care of CHD patients. The information has been collated within a single folder which the reviewers considered good practice. The network recognised the importance of the neonatal services in providing care for CHD patients and have adapted and extended the use of the information in the team's folder. The specialty leads for CHD Anaesthetics are attending Anaesthetic Audit meetings in the Local Cardiology Centres to improve communications and share guidelines.</p> <p>There is a speciality lead for CHD dentistry who is a member of the board; they helped deliver a local training event supported by the British Society of Dentistry. The network considered the close proximity of the dental institute to the level 1 provider enhances communication and support.</p> <p>Specialist training for echocardiography has been included as part of the network educational events attended by the physiologists. The cardiac physiologists in Sheffield are able to perform congenital echos, whereas in Hull the cardiac physiologists from Leeds currently support the outreach clinic to provide echocardiography support and to deliver some training locally.</p>		
<p>108</p>	<p>There is a network quality improvement initiative</p>	<p>Y</p>	<p>Y</p>

Comments

The network manager has developed dashboards for the level 3 providers capturing service information such as waiting times and other performance indicators; all level 3 providers within the network are now submitting data on a regular basis. Data relating to the specialised services quality dashboard (SSQD), waiting times and other clinical outcomes are discussed at the network board meetings. Commissioners also discuss the data at their departmental quarterly meeting. There was an acknowledgement that consistency in data collection needs to be addressed as information relating to length of stay and non-attendance was not being collected in the same way across the network. Network Board meetings are held four times per annum and the Network Clinical Meetings are held twice per annum. Quality improvement initiatives are discussed in all of the six meetings.

One of the quality improvements introduced following concerns of cost pressures relating to prescriptions for Sildenafil and the need for patients to travel to the centre at Leeds to collect them, was for an agreement to be made with Boots chemists whereby the prescriptions were written at the level 1 centre but patients were able to collect the medication from a local pharmacy. This was considered good practice by the reviewers.

General Comments

The YHCHDN is well established and recognised by many involved in CHD services across England as leading on the development of networking, sharing achievements and lessons learned to assist other networks in their development.

The network team described good links with the local charity that has been able to provide practical support such as printing information leaflets in colour, providing support for the CHD website (<http://leedscongenitalhearts.com>) which supports both patients and clinicians involved in the care of CHD patients. The charity has also funded a number of psychologist posts since 2000 and helped support the introduction of home testing kits for warfarin levels.

The reviewers also commend the network for the work undertaken looking at those young patients who go through the transition process who would have potentially been lost to follow up. An audit undertaken in 2017 showed that between 5.7% and 16.8% of the population who were transitioning were “lost to follow up”. The audit concluded that there were a number of factors which contributed to patients not fully participating in the transition process. As a result the network reviewed the policy for transition and introduced some new, proactive ways of working including the data manager producing reports based on the patients being referred to the adult service and those making clinic appointments, text messages being sent to young people to remind them of their appointments and the network administrator contacting the local ACHD centres to collect details of those patients who were due to be seen in the previous 12 months to determine their status. The reviewers were also impressed by the efforts made to target the areas that were identified as having lower engagement with healthcare. The reviewers encourage the team to re audit the lost to follow up to determine if it has been reduced. The reviewers were also impressed with the amount of work that had been already been undertaken; which was apparent both when looking through the available documentation and during the discussion with the representatives from the YHCHDN

Good Practice / Significant Achievements

(List key points covering good practice)

Work completed on the lost to follow up and pro-active data manager providing reports.

Memorandum of understanding which has been agreed and signed by representatives for all CHD providers (level 1 and level 3) within the region which assists in ensuring robust clinical and commissioning engagement into network delivery.

Clear roles and responsibilities for clinical leads and specialist lead roles with dedicated time identified to fulfil the duties.

Meetings with other networks such as neonatal, paediatric and adult services which improves communication and networking.

Work being undertaken to develop clinics within Bradford which should assist in reducing lost to follow up and provides care closer to home.

Significant number of training programmes supported throughout the region, targeting different disciplines and geographical areas for those involved with the care of CHD patients.

Targeted nursing education via identified link nurses who then assist with cascading training to local nursing teams.

Comprehensive guidelines for the joint care of patients delivered by the anaesthetic and dentistry teams to ensure that all patients have dental check-up prior to surgery. Information cards have been developed to provide information about the importance of dental hygiene and the prevention of endocarditis and have been distributed across the region.

PPV resource who are well supported with the network being reactive to patient views, for example, including text in appointments letters to reflect cost of missing appointments.

Patient and family centred care delivery across the network such as the agreement made with Boots chemists whereby the prescriptions are collected from a patient's local pharmacy which reduces travel time.

Comprehensive structure below the board level which supports service improvement.

The development of the adapted and extended information in the cardiac neonatal team's folder to include aspects of cardiac care.

Specify Immediate Risks

An 'Immediate Risk' is an issue that is likely to result in harm to patients or staff or have a direct impact on clinical outcomes and therefore requires immediate action.

CEO/Board Representative risk handed over to at feedback session: *Dr Fiona Campbell, Associate Medical Director, Children's Services*

None Identified.

Specify Serious Concerns

A 'Serious Concern' is an issue that, whilst not presenting an immediate risk to patient or staff safety, could seriously compromise the quality of clinical outcomes of patient care and therefore required urgent action to resolve.

CEO/Board Representative risk handed over to at feedback session: *Dr Fiona Campbell, Associate Medical Director, Children's Services*

None identified.

Areas of Improvement (List areas of improvement)

The network needs to progress current pilot projects on tele-medicine, image transfer and electronic patient records to improve communication and enable participation across the network.

The network should develop formal training for PPV representatives attending the network board meetings in line with the requirements set out by NHS England.

The network should formalise the development and agreement of a five-year work plan with agreed milestones. Consideration should be given to including the commissioner as part of the Network Board which will allow monitoring of the five year work plan.

The network should review the annual work programme to ensure this reflect the previous year.

All network pathways need to be formally agreed through the network governance framework.

The network should consider an increase in working time for both the network manager and lead nurse which may allow further development of the strategic overview of networking

The network should consider including additional details within the operational policy to reflect the criteria for level 1 patients being offered joint clinic access as part of the outreach service.