

Health Services for People with Haemoglobin Disorders

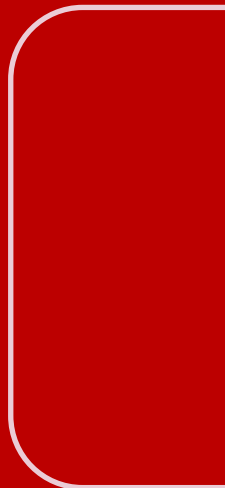
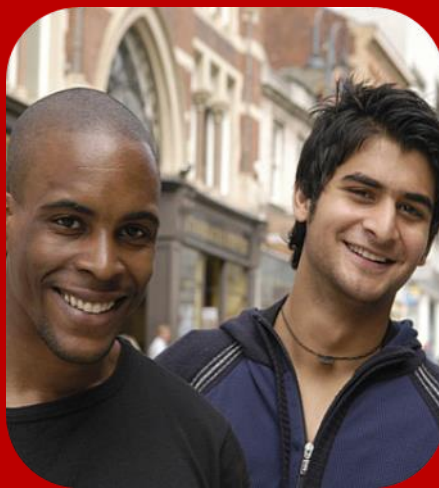
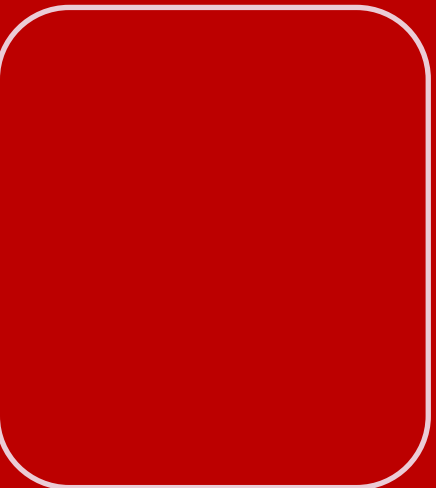
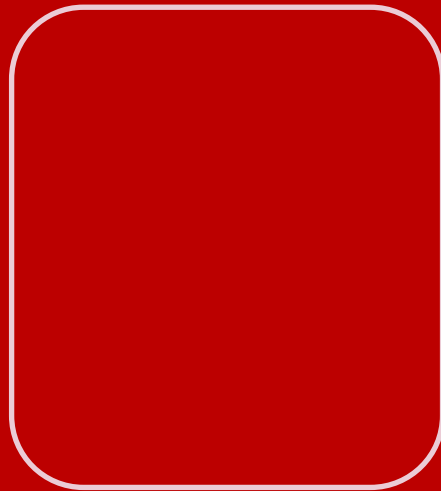
North East England Network

South Tees Hospitals NHS Foundation Trust and
The Newcastle upon Tyne Hospitals NHS Foundation Trust

Visit Date: 6th and 7th May 2015

Report Date: September 2015

Images courtesy of NHS Photo Library



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INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in South Tees Hospitals NHS Foundation Trust and The Newcastle upon Tyne Hospitals NHS Foundation Trust (part of the North East England network), which took place on the 6th and 7th May 2015. The purpose of the visit was to review compliance with the Quality Standards for Health Services for People with Haemoglobin Disorders V2, 2014 which were developed by the UK Forum on Haemoglobin Disorders working with the West Midlands Quality Review Service (WMQRS). The peer review visit was organised by WMQRS on behalf of the UK Forum on Haemoglobin Disorders. The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

Specialist Haemoglobinopathy Centre (SHC)

Accredited Local Haemoglobinopathy Team (A-LHT): A Local Team to which the Specialist Centre has delegated the responsibility for carrying out annual reviews

Local Haemoglobinopathy Teams (LHT): These are sometimes also called 'Linked Providers'

The aim of the Standards and the review programme is to help providers and commissioners of services to improve clinical outcomes and service users' and carers' experiences by improving the quality of services. The report also gives external assurance of the care which can be used as part of organisations' Quality Accounts. For commissioners, the report gives assurance of the quality of services commissioned and identifies areas where developments may be needed.

The report reflects the situation at the time of the visit. The text of this report identifies the main issues raised during the course of the visit. Appendix 1 lists the visiting team and Appendix 2 gives details of compliance with each of the standards and the percentage of standards met.

This report describes services provided or commissioned by the following organisations:

- South Tees Hospitals NHS Foundation Trust
- The Newcastle upon Tyne Hospitals NHS Foundation Trust
- NHS England Specialised Commissioning
- NHS Newcastle Gateshead Clinical Commissioning Group
- NHS South Tees Clinical Commissioning Group

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. Many can be tackled by the use of appropriate service improvement approaches; some require commissioner input. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place and monitoring their implementation liaising, as appropriate, with other commissioners. The lead commissioner in relation to this report is NHS England; Specialised Cancer and Blood.

Acknowledgements

We would like to thank the staff of South Tees Hospitals NHS Foundation Trust and The Newcastle upon Tyne Hospitals NHS Foundation Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks too to the users and carers who took time to come and meet the review team. Thanks are also due to the visiting team (Appendix 1) and their employing organisations for the time and expertise they contributed to this review. The NHS Sickle Cell and Thalassaemia Screening Programme funded this peer review programme.

About West Midlands Quality Review Service

WMQRS is a collaborative venture by NHS organisations in the West Midlands to help improve the quality of health services by developing evidence-based Quality Standards, carrying out developmental and supportive quality reviews - often through peer review visits, producing comparative information on the quality of services and providing development and learning for all involved. More detail about the work of WMQRS is available on www.wmqrns.nhs.uk

HAEMOGLOBIN DISORDERS SERVICES IN NORTH EAST ENGLAND NETWORK

At the time of the visit both South Tees Hospitals NHS Foundation Trust and The Newcastle upon Tyne Hospitals NHS Foundation Trust were commissioned as Specialist Haemoglobinopathy Centres. Care was provided at The James Cook University Hospital, part of the South Tees Hospitals NHS Foundation Trust, and at the Royal Victoria Infirmary, part of The Newcastle upon Tyne Hospitals NHS Foundation Trust.

SOUTH TEES HOSPITALS NHS FOUNDATION TRUST

CHILDREN AND YOUNG PEOPLE

Trust	Reviewed as:	No. of children with sickle cell disease	No. of children with thalassaemia	No. of children on long term red cell transfusions
South Tees Hospitals NHS Foundation Trust The James Cook University Hospital	SHC	7	<5	0

Emergency Care

Children and young people with haemoglobinopathy disorders had direct access to the children's services and did not have to use the Emergency Department (ED). This was facilitated through the day unit where there was an open access policy. Paediatric medical staff were based in the unit and were easily contacted to review children after an initial assessment by day unit nurses. In the event that a child or young person did present in the ED, an Emergency Management of Sickle Cell Disease guideline was available on the Trust intranet site. The pain management protocol in use recommended intravenous opiate analgesia or oral opiate analgesia for severe pain episodes.

In-patient care

In-patient care was provided on ward 21, a 37-bedded ward. It included four one-bedded bays for male teenagers and four for female teenagers as well as a further three designated teenage side rooms. A day room for adolescents was available on the ward. A nurse, competent in cannulation and venepuncture and, in most cases, portacath access, was available. The paediatric critical care unit (PICU) was located next to this ward and any emergency exchange transfusions required (automated and manual) were organised there.

Patients were admitted under the care of the attending consultant paediatrician and were seen within 12 hours with additional support provided by the lead paediatrician and lead haematologist. Cover was provided as required by the haematology Specialist Registrar on call.

Out-patient care

Out-patient clinics were held in the children's out-patient department. Three designated haemoglobinopathy clinics were held per annum. Patients could also be slotted into general paediatric haematology clinics at other times, as required.

Transcranial Doppler (TCD) screening was provided by staff from the Royal Victoria Infirmary (The Newcastle upon Tyne Hospitals NHS Foundation Trust) as an outreach service at South Tees Hospitals NHS Foundation Trust twice a year with additional provision for children to attend the Royal Victoria Infirmary for repeat urgent TCD scanning if required. Magnetic resonance imaging (MRI) scanning for children was undertaken at South Tees Hospitals NHS Foundation Trust.

At the time of the review, no patients had transitioned to the adult service.

Day Unit

The children's day unit was located adjacent to the in-patient ward and was open from 8am until 1am, seven days per week. Designated play specialists were available on most days and a hospital-school liaison service was available Monday to Friday during term times. Open access to the day unit was encouraged and most acute complications were assessed and managed there. If admission was required, the close proximity of the in-patient facilities and joint working of nursing teams allowed for rapid transfer and admission, with a resuscitation area with dedicated staff in the event of acute emergency.

Community-based care

Paediatric community nurses were not employed specifically for the haemoglobinopathy service but were available to undertake home blood tests and portacath access. The specialist nurse visited patients and carers at home for support if necessary.

ADULTS

Trust	Reviewed as:	No. of adults with sickle cell disease	No. of adults with thalassaemia	No. of adults on long term red cell transfusions
South Tees Hospitals NHS Foundation Trust	SHC	14	<5	<5

Emergency Care

Adults with haemoglobinopathy disorders had direct access to adult haematology services and did not have to use the Emergency Department (ED). In the event that a patient did present in the ED, an Emergency Management of Sickle Cell Disease guideline was available on the Trust intranet site.

In-patient care

In-patient care was provided on ward 33, a 19-bedded haematology ward. Patients with haemoglobinopathies were prioritised for beds on the ward. Three beds were designated for teenagers and young adults. Daily ward rounds were carried out by a senior house officer and a haematology specialist trainee. Consultant cover was provided by the consultant of the week and the haemoglobinopathy lead clinician was available for advice or to review new patients.

Patients admitted out of hours were reviewed by the Hospital at Night team. The non-resident on-call specialist registrar would also come in and review any new patients admitted with sickle cell disease. Weekend ward rounds were delivered by the on-call haematology team.

Out-patient care

Out-patient care was provided in the haematology day unit which was open Monday to Friday, 8.30am until 5pm. A nurse competent in cannulation, venepuncture and portacaths access was always available.

The day unit was staffed by either Specialist Registrars in haematology or Specialty Doctors. Nurse prescribers were available to administer first dose opiates to patients in severe pain.

Community-based care

There were no designated community haemoglobinopathy services but the specialist nurse undertook home visits to patients and carers if necessary. The haematology outreach nursing service was also available to provide support to patients if required.

CHILDREN AND YOUNG PEOPLE

Trust	Reviewed as:	No. of children with sickle cell disease	No. of children with thalassaemia	No. of children on long term red cell transfusions
The Newcastle upon Tyne Hospitals NHS Foundation Trust Royal Victoria Infirmary Great North Children's Hospital	SHC	23	<5	
City Hospitals Sunderland NHS Foundation Trust	LHT		<5 (seen in Newcastle for annual review)	

Emergency care

Children and young people had open access for the assessment of acute episodes to the paediatric assessment unit embedded within the haemophilia centre at the Royal Victoria Infirmary. Families were encouraged to contact the paediatric nurse specialist for a telephone assessment and would then be seen by her for initial assessment. The paediatric medical team, lead haematology consultant or haematology Registrar were contacted for further management. Unwell children were encouraged to attend the children's Emergency Department (ED) and sick children seen on the day unit were referred to the ED, where they were seen by the paediatric medical team and further management discussed with the haematologist. The attending consultant paediatrician reviewed the patient within 12 hours. Additional support was provided by the haematology Specialist Registrar (who worked a one in seven rota). Haematology consultant cover was provided by the on-call consultant, part of the one-in-six non-malignant haematology rota. The pain management protocol in use recommended intravenous opiate analgesia or oral opiate analgesia for severe pain episodes.

In-patient care

Children and young people requiring in-patient care were admitted to the Great North Children's Hospital under the joint care of the consultant paediatrician of the week, who reviewed the patient daily, and the paediatric haematology team. Protocols for the management of sickle cell disease were available and all in-patients were reviewed within 24 hours by a consultant haematologist, including at weekends. There was no designated ward for haematology patients. High dependency and paediatric intensive care were available on site.

Out-patient care

Clinics were held six times a year and run from the Haemophilia Centre at the Royal Victoria Infirmary where children and young people were seen in the designated assessment room. At the time of the visit no paediatrician attended these clinics. Trans-Cranial Doppler screening was available at three-monthly clinics run from the Haemophilia Centre. This service was provided by a designated team based in the neuroradiology department.

Day Unit

Children requiring regular transfusion were managed on the paediatric day unit facility. Transfusions were coordinated on an out-patient clinic day. During the clinic appointment the child was seen by the lead haematologist and blood prescribed. The nurse specialist was responsible for coordinating this process.

Community based care

New patients identified by the screening programme were offered an appointment for assessment and follow up in partnership with the general practitioner and maternity services. Families of newly diagnosed babies received a home visit. This was coordinated by the specialist midwife.

All schools of children with sickle cell disease were offered a visit for staff education by the haemoglobinopathy specialist practitioner or the paediatric haematology nurse specialist.

ADULTS

Trust	Reviewed as:	No. adults with sickle cell disease	No. adults with thalassaemia	No. adults on long term red cell transfusions
The Newcastle upon Tyne Hospitals NHS Foundation Trust	SHC	16	<5	<5

Emergency care

Patients had open access for the assessment of acute incidents via the Royal Victoria Infirmary (RVI) Haemophilia Centre/Haematology Unit 'in hours' and via the Emergency Department at the RVI 'out of hours', where patients were triaged to the medical assessment unit. Cover was provided by junior medical staff and the haematology Specialist Registrar (who worked a one-in-seven rota). Consultant cover was provided by the on-call consultant, as part of the one-in-six non-malignant haematology rota.

In-patient care

Patients requiring admission were transferred to the haematology in-patient ward (33) at the Freeman Hospital (The Newcastle upon Tyne Hospitals NHS Foundation Trust) or to the medical ward in the RVI depending on clinical requirement and bed availability. Protocols for the management of sickle cell disease were available and all in-patients were reviewed within 24 hours by a consultant haematologist.

Out-patient care

A three monthly joint orthopaedic/haematology clinic was in place and weekly joint obstetric/haematology clinics were held.

Community based care

There was no formal provision of community based care.

VIEWS OF SERVICE USERS AND CARERS

The visiting team met a small number of patients and carers with sickle cell disease on both sites and received feedback from them. Common themes raised by patients and carers in South Tees Hospitals NHS Foundation Trust were:

- Patients were very appreciative about the care that they received. Staff outside the core team were not very knowledgeable about their condition.
- Patients did not have a written care plan or pain plan.
- Patients understood the protocols about what to do in an emergency and changing appointments.
- Greater access to written information was needed, especially on the condition and available benefits.
- Greater access to a psychologist was wanted.
- Some patients felt isolated and would appreciate the development of a support group.
- The services at the Trinity Holistic Centre were appreciated by the patients.

Common themes raised by patients and carers in The Newcastle upon Tyne Hospitals NHS Foundation Trust were:

- Patients greatly appreciated the service and the care given by the team. The patients met by reviewers had not been acutely ill and therefore had not used the emergency system for some time.
- Patients appreciated the parent group meetings which had been very encouraging.
- Patients did not have a written care plan.
- Further information for patients around sickle cell disease was wanted, to help to allay fears and misconceptions about the condition, particularly around life expectancy.

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REVIEW VISIT FINDINGS

NETWORK

General Comments and Achievements

The North East England network covered a large geographical area with relatively small numbers of patients with haemoglobin disorders cared for in Middlesbrough and Newcastle plus a small number of patients who routinely attended City Hospitals Sunderland NHS Foundation Trust but had annual reviews in Newcastle. Joint care between Sunderland and Newcastle worked well. Relationships with haemoglobin disorders and haematology teams across the region were also good.

Progress since last visit

The last review in March 2012 had suggested that both Trusts link with a larger centre for the care of people with haemoglobinopathies but little progress had been made on this issue

Concerns

- 1 Arrangements to link with another Specialist Haemoglobinopathy Centre were not in place so sharing of guidelines, network audits or shared educational activity was not undertaken.

Further Consideration

- 1 Closer network working between South Tees Hospitals NHS Foundation Trust and The Newcastle upon Tyne Hospitals NHS Foundation Trust could be helpful. For example, joint nurse posts could support the workload on both sites, provide cover for absences and support development of consistent policies and practices, training and audit. Arrangements for sharing support from a health psychologist with an interest in haemoglobin disorders could also be helpful.
- 2 There was no formal agreement between South Tees Hospitals NHS Foundation Trust and The Newcastle upon Tyne Hospitals NHS Foundation Trust and, at the time of the visit, they operated as an informal clinical network.

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SPECIALIST TEAM: SOUTH TEES HOSPITALS NHS FOUNDATION TRUST (CARE OF CHILDREN, YOUNG PEOPLE AND ADULTS)

General Comments and Achievements

Good clinical leadership was in place for both adult and paediatric services with highly motivated specialist nursing support. Services were very much appreciated by patient and carers.

Newly refurbished facilities were of a high standard for both services. The organisation and position of day care, in-patient care and critical care for children and young people was particularly good. The adolescent unit provided a designated teenage and young person's area.

All patients had access to the Trinity Holistic Centre which provided counselling services and a range of alternative therapies. An outreach Trans-Cranial Doppler screening programme had been established which enabled 100% of eligible patients to be scanned.

Progress since Last Visit

The previous review of services for adults with haemoglobin disorders took place in March 2012 and progress since that time included the refurbishment of the adult haematology out-patient and day unit. In-patient care had moved to a larger (19 bedded) haematology ward, incorporating designated beds for teenagers and young adults.

A clinical nurse specialist post for red cell disorders had been secured on a permanent basis. The development and implementation of nurse prescribing for transfusions had reduced waiting times.

Good Practice

- 1 An excellent patient information booklet was in use across both services
- 2 Individualised pain management protocols were available on the Trust's 'inflex' system.
- 3 Both services had easy and direct access to day units and in-patient care for patients requiring medical attention. Patients did not have to attend the Emergency Department.

Immediate Risks: No immediate risks were identified

Concerns

- 1 Many of the expected guidelines for both services were either not in place or lacked sufficient detail:
 - a. There were no guidelines for the care of patients with thalassaemia.
 - b. The acute care guidelines for both services lacked clarity and did not include information specific to either the care of children and young people, or adult patients. The guidelines for the paediatric service, in particular, were reliant on the availability of the lead clinician.
 - c. The exchange protocol contained little practical detail on the how to set up and complete an exchange. The process described in the available protocol was more appropriate to an adult procedure.
 - d. Guidelines for management of chronic complications with appropriate referral criteria to specialist services were not available. Formal arrangements for specialist and supra-specialist advice were not yet in place although larger specialist centres in London were sometimes contacted. This issue was identified in 2012 and had not yet been addressed.
- 2 Cover for the lead nurse for the service was not robust.
- 3 There was no access to either a clinical or health psychologist with an interest in haemoglobin disorders for adult patients.
- 4 Patients did not routinely receive copies of their care plans or clinic letters.
- 5 An education and training programme for all health professionals involved in the care of children and young people and adults with haemoglobinopathies was not yet in place.
- 6 The service did not collect the expected data and not all audits had been carried out.

Further Consideration

- 1 As part of developing links with a larger centre, reviewers suggested that the service could consider requesting relevant clinical guidelines and adapting them for local circumstances.
- 2 Some patient information resources were available but not easily accessible by patients unless specifically requested.

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SPECIALIST TEAM: THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST (CARE OF CHILDREN, YOUNG PEOPLE AND ADULTS)

General Comments and Achievements

The haemoglobinopathy service was part of a large tertiary haematology department and a small team provided care for people with haemoglobin disorders of all ages. The service had been incorporated into the Haemophilia Centre and patients had access to a good physiotherapy service if required. A consultant in non-

malignant haematology had been appointed to the service shortly before the review with job-planned sessions for care of people with haemoglobin disorders. Patient feedback about the service was good.

Progress since last visit

The previous review of services for adults with haemoglobin disorders took place in March 2012. Since that visit the service had started entering patient data onto the National Haemoglobin Registry, including annual reviews and adverse events.

Good Practice

- 1 A well-structured patient passport contained comprehensive information about patients with haemoglobinopathies and was available both electronically and within patient notes. A hard copy of the passport was also given to each patient.

Immediate Risks: No immediate risks were identified

Concerns

- 1 At the time of the visit there was no designated consultant paediatrician support for the service, although the lead adult consultant did have job plan time allocated for the care of children and young people with haemoglobin disorders.
- 2 Many of the expected guidelines for both services were not in place, lacked sufficient detail or did not reflect clinical practice in most centres:
 - a. The acute care guidelines lacked clarity and were reliant on the availability of the lead clinician.
 - b. Guidelines with indications and a referral pathway for automated exchange were not available.
 - c. Adult and paediatric aspects of guidelines were not always clearly identified.
 - d. Guidelines for management of chronic complications with appropriate referral criteria to specialist services were not available. Formal arrangements for specialist and supra-specialist advice were not yet in place although larger specialist centres in London were sometimes contacted. This issue was identified in 2012 and had not yet been addressed.
- 3 There was limited access to a clinical or health psychologist with an interest in haemoglobin disorders.
- 4 Available facilities were of concern for two reasons:
 - a. Children and young people were seen in the Haemophilia Centre at the Royal Victoria Infirmary within the Trust. However there was limited capacity to review patients attending with acute complications and elective transfusions were administered in a separate children's day care facility.
 - b. Adult patients with complex needs were admitted to the Freeman Hospital, away from the haemoglobinopathy team based at the Royal Victoria Infirmary site. This made the review of patients difficult as it involved a round trip of approximately 40 to 50 minutes between the two sites.
- 5 A programme of education and training for all health professionals involved in the care of patients with haemoglobin disorders was not yet in place.
- 6 The service did not collect the expected data and a programme of audits of the care of people with haemoglobin disorders was not yet in place.

Further Consideration

- 1 As part of developing links with a larger centre, reviewers suggested that the service could consider requesting relevant clinical guidelines and adapting them for local circumstances.

- 2 Reviewers considered that there may be an over-reliance on intravenous morphine for pain control. Reviewers suggested the service should consider other parenteral routes and amend guidelines accordingly.
- 3 The patient passport was based upon an end of life care document and contained references to end of life care and 'do not attempt resuscitation' (DNAR) which reviewers suggested should be removed.
- 4 The Trust did not yet have a programme of transition to adult services. The haemoglobin disorders team cared for children, young people and adults but other aspects of the service provided were different as young people transitioned to adult care. Reviewers suggested that appropriate guidelines and information for patients would be helpful. The service did manage a small number of patients who were of an appropriate age to start the transition process.

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COMMISSIONING

General Comments and Achievements

The specialised commissioner for the region had a clear understanding of the service and the need for a split site Specialist Haemoglobinopathy Centre arrangement in the context of geography and poor transport links across the region. It was, however, difficult to disaggregate activity data for the service from general haematology work commissioned by Clinical Commissioning Groups.

An outreach Transcranial Doppler (TCD) service had been established from The Newcastle upon Tyne Hospitals NHS Foundation Trust to South Tees Hospitals NHS Foundation Trust. Agreement had also been reached to provide a Ferriscan service for the two centres.

Concerns

- 1 None of the commissioning standards were met at this visit.

Further Consideration

- 1 There was no formal agreement between South Tees Hospitals NHS Foundation Trust and The Newcastle upon Tyne Hospitals NHS Foundation Trust and, at the time of the visit, they operated as an informal clinical network.

APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Clinical Lead/s

Dr Banu Kaya	Consultant Haematologist	Barts Health NHS Trust
Dr Josh Wright	Consultant Haematologist	Sheffield Teaching Hospitals NHS Foundation Trust

Visiting Team

Edith Aimiwu	Paediatric Haemoglobinopathy Clinical Nurse Specialist	Whittington Health NHS Trust
Dr Claire Chapman	Consultant Haematologist	University Hospitals of Leicester NHS Trust
Verna Davis	Nurse Manager	Central Manchester University Hospitals NHS Foundation Trust
Dr Baba Inusa	Paediatric Haematologist	Guy's and St Thomas' NHS Foundation Trust
Natasha Lewis	Lead Nurse Sickle Cell and Thalassaemia	Homerton University Hospital NHS Foundation Trust
Elaine Miller	UKTS National Coordinator	UK Thalassaemia Society
Philip Udeh	Service User	
Neil Westerdale	Advanced nurse practitioner	Guy's and St Thomas' NHS Foundation Trust

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APPENDIX 2 COMPLIANCE WITH THE QUALITY STANDARDS

Analyses of percentage compliance with the Quality Standards should be viewed with caution as they give the same weight to each of the Quality Standards. Also, the number of Quality Standards applicable to each service varied depending on the nature of the service provided. Percentage compliance also takes no account of 'working towards' a particular Quality Standard. Reviewers often comment that it is better to have a 'No, but', where there is real commitment to achieving a particular standard, than a 'Yes, but' – where a 'box has been ticked' but the commitment to implementation is lacking. With these caveats, table 1 summarises the percentage compliance for each of the services reviewed.

Table 1 - Percentage of Quality Standards met

Adult Service	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	86	40	47
South Tees Hospitals NHS Foundation Trust	(43)	(19)	(44)
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	(43)	(21)	(49)
Haemoglobin Disorders Clinical Network	9	2	22
Commissioning	3	0	0
Total	98	42	43

Service for Children & Young People	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	96	47	49
South Tees Hospitals NHS Foundation Trust	(46)	(23)	(50)
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	(50)	(24)	(48)
Haemoglobin Disorders Clinical Network	9	2	22
Commissioning	3	0	0
Total	108	49	45

Pathway and Service Letters

HN-	Specialist services for People with Haemoglobin Disorders
HY-	Haemoglobin Disorders: Network
HZ-	Haemoglobin Disorders: Commissioning

Topic Sections

Each section covers the following topics:

-100	Information and Support for Patients and Carers
-200	Staffing
-300	Support Services
-400	Facilities and Equipment
-500	Guidelines and Protocols
-600	Service Organisation and Liaison with Other Services
-700	Governance

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SPECIALIST SERVICES FOR PEOPLE WITH HAEMOGLOBIN DISORDERS – SOUTH TEES HOSPITALS NHS FOUNDATION TRUST

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-101 All	<p>Haemoglobin Disorder Service Information</p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: <ol style="list-style-type: none"> i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent) v. Give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns vi. Get involved in improving services (QS HN-199) 	N	Information for 'h, iii' and interpreter services ('h, iv') were not available.	N	Information for 'h, iii' and interpreter services ('h, iv') were not available.

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-102 All	<p>Information about Haemoglobin Disorders</p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> a. A description of the condition (SC or T), how it might affect the individual and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Splenic palpation and Trans-Cranial Doppler scanning (children only) e. Transfusion and iron chelation f. Possible complications, including priapism and complications during pregnancy g. Health promotion, including: <ol style="list-style-type: none"> i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Stopping smoking h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions 	N	The patient information booklet was good however there was no information for patients with thalassaemia.	N	The patient information booklet was good however there was no information for patients with thalassaemia.

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-103 All	<p>Information for Primary Health Care Team</p> <p>Written information should be sent to the patient's primary health care team covering available local services and</p> <ol style="list-style-type: none"> a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b. Side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on hydroxycarbamide and iron chelation therapy (if being prescribed by GPs). d. Immunisations e. Indications and arrangements for seeking advice from the specialist service 	Y		Y	
HN-104 All	<p>Care Plan</p> <p>All patients should be offered:</p> <ol style="list-style-type: none"> a. An individual care plan or written summary of their annual review including: <ol style="list-style-type: none"> i. Information about their condition ii. Plan for management in the Emergency Department iii. Planned acute and long-term management of their condition, including medication iv. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed <p>The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).</p>	N	<p>Comprehensive, individualised care plans were available on the Trust 'infoflex' system. This was not reflected in the guidelines. Patients did not systematically receive copies of their plans or clinic letters.</p> <p>See main report.</p>	N	<p>Comprehensive, individualised care plans were available on the Trust 'infoflex' system. This was not reflected in the guidelines. Patients did not systematically receive copies of their plans or clinic letters.</p> <p>See main report.</p>

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-105 All	<p>School Care Plan (Paediatric Services Only)</p> <p>A School Care Plan should be agreed for each child or young person covering, at least:</p> <ol style="list-style-type: none"> School attended Medication, including arrangements for giving / supervising medication by school staff What to do in an emergency whilst in school Arrangements for liaison with the school 	N/A		N	Medication arrangements were not formally documented but were discussed on an individual basis.
HN-106 SHC (A-LHT)	<p>Transition to Adult Services</p> <p>Young people transferring to the care of adult services should be offered written information covering at least:</p> <ol style="list-style-type: none"> Their involvement in the decision about transfer and, with their agreement, involvement of their family or carer A joint meeting between children's and adult services to plan the transfer A named coordinator for the transfer of care A preparation period prior to transfer Arrangements for monitoring during the time immediately after transfer 	Y		Y	

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-107 SHC	<p>Information about Trans-Cranial Doppler Ultrasound</p> <p>Written information should be offered to patients and their carers covering:</p> <ol style="list-style-type: none"> Reason for the scan and information about the procedure Details of where and when the scan will take place and how to change an appointment Staff who will be present and will perform the scan Any side effects Informing staff if the child is unwell or has been unwell in the last week How, when and by whom results will be communicated 	N/A		Y	
HN-199 All	<p>Involving Patients and Carers</p> <p>The service's involvement of patients and carers should include:</p> <ol style="list-style-type: none"> Mechanisms for receiving feedback from patients and carers An annual patient survey (or equivalent) Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service Examples of changes made as a result of feedback and involvement of patients and carers 	N	Mechanisms for collecting feedback from patients and carers were not embedded in the service. There was no evidence of changes made as a result of feedback.	N	Mechanisms for collecting feedback from patients and carers were not embedded in the service. There was no evidence of changes made as a result of feedback.

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-201 All	<p>Lead Consultant</p> <p>A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have session/s identified for this role within their job plan.</p>	Y		Y	However support for paediatrician support for services was limited.
HN-202 All	<p>Cover for Lead Consultant</p> <p>Cover for absences of the lead consultant should be available. In SHCs this should be a named deputy within the SHC with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHC. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHC advice and support.</p>	Y		Y	As above.

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-203 All	<p>Lead Nurse</p> <p>A lead nurse should have appropriate time available for their leadership role and:</p> <ul style="list-style-type: none"> a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. RCN competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only) 	N	Evidence that the lead nurse had the expected competences was not available.	N	Evidence that the lead nurse had the expected competences was not available.

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-204 All	<p>Staffing Levels and Competences</p> <p>The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including:</p> <ol style="list-style-type: none"> Medical staffing for clinics and regular reviews Medical staffing for emergency care, in and out of hours Nurse staffing on the ward and day unit Clinical nurse specialist/s with responsibility for the acute service Clinical nurse specialist/s with responsibility for the community service Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion. Clinical or health psychologist with an interest in haemoglobin disorders <p>Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT).</p> <p>Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders.</p> <p>Cover for absences should be available.</p>	N	<p>RCN (Royal College of Nursing) competences had not yet been implemented. There was no psychology support available except via a referral from a GP.</p> <p>There was no cover available for'd'.</p> <p>See main report.</p>	N	<p>RCN (Royal College of Nursing) competences had not yet been implemented. There was no cover available for'd'.</p> <p>See main report.</p>
HN-205 All	<p>Competences and Training</p> <p>A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders (QS HN-204).</p>	N	A training plan was not in place.	N	A training plan was not in place.

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-206 SHC	Specialist Advice During normal working hours a consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients.	Y		Y	
HN-207 All	Training for Emergency Department Staff The service should offer regular training in the care of patients with haemoglobin disorders to: a. Clinical staff in the Emergency Department b. Nursing staff on general wards to which patients with haemoglobin disorders may be admitted	N	Regular training for Emergency Department (ED) staff was not in place. Patients had direct access to the wards and so did not routinely have to access the ED.	N	Regular training for Emergency Department (ED) staff was not in place. Patients had direct access to the wards and so did not routinely have to access the ED.
HN-208 All	Safeguarding Training All staff caring for people with haemoglobinopathies should have undertaken appropriate training in: a. Safeguarding children and/or vulnerable adults (as applicable) b. Equality and diversity	Y		Y	
HN-209 SHC	Doctors in Training The service should ensure that doctors in training have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y	The Trust was not able to provide doctors in training with the opportunity to gain appropriate competences. An optional two week placement at a high prevalence specialist centre was available.	Y	The Trust was not able to provide doctors in training with the opportunity to gain appropriate competences. An optional two week placement at a high prevalence specialist centre was available.

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-210 SHC	<p>Trans-Cranial Doppler Ultrasound Competences (Paediatric Services Only)</p> <p>Sufficient staff with appropriate competences for Trans-Cranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.</p>	N/A		N/A	Transcranial Doppler scanning was provided on an outreach basis by Newcastle Upon Tyne Hospitals NHS Foundation Trust.
HN-299 All	<p>Administrative, Clerical and Data Collection Support</p> <p>Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.</p>	Y		Y	
HN-301 All	<p>Support Services</p> <p>Timely access to the following services should be available:</p> <ol style="list-style-type: none"> Psychologist with an interest in haemoglobinopathies Social worker Leg ulcer service Play specialist (children's services only) Chronic pain team Dietetics Physiotherapy Occupational therapy Mental health services (adult and CAMHS) <p>In Specialist Centre's these staff should have specific competences in the care of people with haemoglobin disorders and sufficient time for patient care and for attending multi-disciplinary meetings (HN-602) if required.</p>	N	There was no access to a psychologist with an interest in haemoglobinopathies.	Y	

	South Tees Hospitals NHS Foundation Trust	Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-302 SHC	<p>Specialist On-site Support</p> <p>Access to the following specialist staff and services should be available on the same hospital site as the specialist team:</p> <ul style="list-style-type: none"> a. Manual exchange transfusion (24/7) b. Acute pain team including specialist monitoring of patients with complex analgesia needs c. Consultant obstetrician with an interest in care of people with haemoglobin disorders d. Respiratory physician with interest in chronic sickle lung disease e. High dependency care, including non-invasive ventilation f. Intensive care (note 2) 	Y		Y	

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-303 SHC A-LHT	<p>Specialist Services - Network</p> <p>Access to the following specialist staff and services should be available:</p> <ul style="list-style-type: none"> a. Erythrocytapheresis b. Pulmonary hypertension team c. Fertility, contraception and sexual health services, including pre-implantation genetic diagnosis d. Consultant cardiologist e. Consultant endocrinologist f. Consultant hepatologist g. Consultant neurologist h. Consultant ophthalmologist i. Consultant nephrologist j. Consultant urologist with expertise in managing priapism and erectile dysfunction k. Orthopaedic service l. Specialist imaging, including <ul style="list-style-type: none"> i. MRI tissue iron quantification of the heart and liver ii. Trans-Cranial Doppler ultrasonography (children) m. Neuropsychologist n. DNA studies o. Polysomnography and ENT surgery p. Bone marrow transplantation services <p>Specialist services should have an appropriate level of specialist expertise in the care of people with haemoglobin disorders.</p>	Y	Patients who required access to 'b' and 'j' were referred to other larger centres. See also main report.	Y	Patients who required access to 'b' and 'j' were referred to other larger centres. See also main report.

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-304 All	Laboratory Services UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y		Y	
HN-401 All	Facilities Available The environment and facilities in phlebotomy, out-patient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child friendly environment, including toys and books / magazines for children and young people of all ages.	Y	See main report.	Y	See main report.
HN-402 All	Facilities for Out of Hours Care Facilities should be available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	N	Facilities were open Monday to Friday, 8.00am to 5.00pm.	Y	Facilities were open seven days a week until 1.00am.

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-501 SHC A-LHT	<p>Transition Guidelines</p> <p>Network-agreed guidelines on transition to adult care should be in use covering at least:</p> <ul style="list-style-type: none"> a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams 	Y		Y	
HN-502 All	<p>Monitoring Checklists</p> <p>Checklists should be in use for:</p> <ul style="list-style-type: none"> a. First out-patient appointment (SHC & A-LHT only) b. Routine monitoring c. Annual review (SHC & A-LHT only) <p>Use of the checklists should cover both clinical practice and information for patients and families.</p>	Y	Checklists were in place but some clinic information was not included, for example, splenic palpation.	Y	Checklists were in place but some clinic information was not included, for example, splenic palpation.

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-503 LHT	<p>Clinical Guidelines: LHT Management and Referral</p> <p>Network-agreed guidelines on routine out-patient monitoring and management between annual reviews should be in use which specify the indications for telephone advice, early referral and immediate transfer to the Specialist Centre.</p>	N/A		N/A	
HN-504 All	<p>Transfusion Guidelines</p> <p>Transfusion guidelines should be in use covering:</p> <ol style="list-style-type: none"> Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion Offering access to exchange transfusion to patients on long-term transfusions Protocol for carrying out an exchange transfusion Hospital transfusion policy Investigations and vaccinations prior to first transfusion Review by specialist nurse or doctor prior to transfusion to ensure each transfusion is appropriate. Areas where transfusions will usually be given Recommended number of cannulation attempts 	N	<p>Although a guideline was in place it did not contain sufficient detail and required updating.</p> <p>See main report.</p>	N	<p>Paediatric specific transfusion guidelines were not in place. There was no phlebotomy advice for cannulation in children ('h').</p> <p>See main report.</p>

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-505 All	<p>Chelation Therapy</p> <p>Network-agreed clinical guidelines on chelation therapy should be in use covering:</p> <ul style="list-style-type: none"> a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT/SHC. g. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible. 	Y		Y	

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-506 All	<p>Clinical Guidelines: Acute Complications</p> <p>Network-agreed clinical guidelines on the management of acute complications should be in use covering at least:</p> <p>For patients with sickle cell disease:</p> <ol style="list-style-type: none"> Acute pain Fever, infection and overwhelming sepsis Acute chest syndrome Abdominal pain and jaundice Acute anaemia Stroke and other acute neurological events Priapism Acute renal failure Haematuria Acute changes in vision Acute splenic sequestration (children only) <p>For patients with thalassaemia:</p> <ol style="list-style-type: none"> Fever, infection and overwhelming sepsis Cardiac, hepatic or endocrine decompensation 	N	<p>There were no guidelines for thalassaemia.</p> <p>The available guidelines did not include all relevant information such as patient profiles available on 'infoflex' and indications for the use of portacaths.</p>	N	<p>There were no guidelines for thalassaemia.</p> <p>The available guidelines did not include all relevant information such as patient profiles available on 'infoflex' and indications for the use of portacaths.</p>
HN-507 All	<p>Specialist Management Guidelines</p> <p>Network-agreed clinical guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia:</p> <ol style="list-style-type: none"> During anaesthesia and surgery Who are pregnant Receiving hydroxycarbamide therapy 	N	<p>Local guidelines did not reference national guidelines. Guidelines for 'c' were in draft form and insufficient for routine clinical practice.</p>	N	<p>Local guidelines did not reference national guidelines. Guidelines for 'c' were in draft form and insufficient for routine clinical practice.</p>

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-508 All	<p>Clinical Guidelines: Chronic complications</p> <p>Network-agreed clinical guidelines on the management of chronic complications should be in use covering at least:</p> <ul style="list-style-type: none"> a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain i. Liver disease j. Growth delay / delayed puberty (children only) k. Enuresis (children only) 	N	Guidelines were not available.	N	Guidelines were not available.
HN-509 SHC	<p>Referral for Consideration of Bone Marrow Transplantation</p> <p>Guidelines for referral for consideration of bone marrow transplantation should be in use.</p>	N	Guidelines were not available.	N	Guidelines were not available.
HN-510 All	<p>Thalassaemia Intermedia</p> <p>Network-agreed clinical guidelines for the management of thalassaemia intermedia should be in use, covering:</p> <ul style="list-style-type: none"> a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy 	N	Guidelines were not yet in place.	N	Guidelines were not yet in place.

	South Tees Hospitals NHS Foundation Trust	Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-511 All	<p>Clinical Guideline Availability</p> <p>Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, clinic and ward areas.</p>	N	Guidelines were not available for the management of chronic complications.	N	Guidelines were not available for the management of chronic complications.

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-512 SHC	<p>Trans-Cranial Doppler Ultrasound Guidelines (Paediatric Services Only)</p> <p>Guidelines on Trans-Cranial Doppler ultrasound should be in use covering at least:</p> <ol style="list-style-type: none"> Identification of ultrasound equipment and maintenance arrangements Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-210) Arrangements for supervision of doctors in training performing Trans-Cranial Doppler ultrasound Ensuring all patients are given relevant information (QS HN-107) Use of an imaging consent procedure Guidelines on cleaning ultrasound probes Arrangements for recording and storing images and ensuring availability of images for subsequent review Reporting format, including whether mode performed was imaging or non-imaging Arrangements for documentation and communication of results Internal systems to assure quality, accuracy and verification of results Participation in the National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler ultrasound (when established) or local peer review arrangements (until NQAS established) 	N/A		N/A	Trans-Cranial Doppler scanning was provided on an outreach basis by Newcastle Upon Tyne Hospitals NHS Foundation Trust.

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-601 All	<p>Service Organisation</p> <p>A service organisation policy should be in use covering arrangements for:</p> <ul style="list-style-type: none"> a. 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by a specialist SHC (SHC only) b. Ensuring all patients are reviewed by a senior haematology decision-maker within 12 hours of acute admission c. Patient discussion at multi-disciplinary team meetings (QS HN-602) d. Out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population e. Arrangements for liaison with community paediatricians and with schools (children's services only) f. 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated g. Follow up of patients who do not attend h. Transfer of care of patients who move to another area, including communication with all SHC, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHC, LHT and community services who will be taking over their care. i. Accessing specialist advice (QS HN-206) j. Two-way communication of patient information between SHC and LHTs k. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together 	N	No operational policy was in place.	N	No operational policy was in place.

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-602 All	Multi-Disciplinary Meetings Multi-disciplinary team meetings should be held regularly involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, other members of the service team (QS HN-204) and representatives of support services (QS HN-301).	N	Multi-disciplinary meetings, as envisaged by this Quality Standard, were not yet in place.	N	Multi-disciplinary meetings, as envisaged by this Quality Standard, were not yet in place.
HN-603 All	Service Level Agreement with Community Services A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	N/A		N/A	
HN-604 All	Network Review and Learning Meetings At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).	Y		Y	
HN-605 SHC	Neonatal screening programme review meetings The SHC should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results (HN-704), identify issues of mutual concern and agree action.	N/A		Y	Twice yearly meetings took place.

	South Tees Hospitals NHS Foundation Trust	Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-701 SHC	<p>Data Collection</p> <p>Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events.</p>	Y		Y	
HN-702 All	<p>Annual Data Collection - Activity</p> <p>The service should monitor on an annual basis:</p> <ol style="list-style-type: none"> Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances Length of in-patient stays Re-admission rate 'Did not attend' rate for out-patient appointments 	N	Data were not yet collected and monitored.	N	Data were not yet collected and monitored.

Ref	South Tees Hospitals NHS Foundation Trust	Adult Service		Service for Children and Young People	
	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-703 SHC	<p>Annual Data Collection – Network Patient Data</p> <p>The SHC should monitor on an annual basis, separately for sickle cell disease and thalassaemia:</p> <ol style="list-style-type: none"> a. Number of patients under active care in the network at the start of each year b. Number of new patients accepted by network services during the course of the year: <ol style="list-style-type: none"> i. Births ii. Transferred from another service iii. Moved into the UK c. For babies identified by the screening service: <ol style="list-style-type: none"> i. Date seen in clinic ii. Date offered and prescribed penicillin d. Number of network patients who had their comprehensive annual review undertaken and documented in the last year e. Number of network patients on long-term transfusion f. Number of network patients on chelation therapy g. Number of network patients on hydroxycarbamide h. Number of paediatric patients (HbSS and HbSB) who have had Trans-Cranial Doppler ultrasonography undertaken within the last year i. Number of pregnancies in network patients j. Number of network patients whose care was transferred to another service during the year k. Number of network patients who died during the year l. Number of network patients lost to follow up during the year 	N	Data were collected and monitored but at the time of the visit this was incomplete.	N	Data were collected and monitored but at the time of the visit this was incomplete.

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-704 All	<p>Audit Clinical audits covering the following areas should have been undertaken within the last two years:</p> <p>Achievement of screening follow-up standards:</p> <ul style="list-style-type: none"> a. At least 90% of infants with a positive screening result attend a local clinic by three months of age b. At least 90% of cases of HbSS and HbSC have confirmation of result documented in clinical notes by six months of age c. Less than 10% of cases on registers lost to follow up within the past year <p>For patients with sickle cell disease:</p> <ul style="list-style-type: none"> d. Proportion of patients with recommended immunisations up to date e. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required f. Compliance with NICE Clinical Guideline on the management of acute pain, including proportion of patients attending in acute pain who received first analgesia within 30 minutes of arrival, and achieved adequate pain control within two hours of arrival g. Availability of extended red cell phenotype in all patients h. Proportion of children: <ul style="list-style-type: none"> i. at risk of stroke who have been offered and/or are on long-term transfusion programmes ii. who have had a stroke <p>For patients with thalassaemia:</p> <ul style="list-style-type: none"> i. Evidence of effective monitoring of iron overload, including imaging (QS HN-505) j. Proportion of patients who have developed new iron-related complications in the preceding 12 months <p>All patients:</p> <ul style="list-style-type: none"> k. Waiting times for transfusion 	N	Not all the expected audits had been carried out.	N	Audits had not been carried out for 'f' or 'i'.

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-705 All	<p>Guidelines Audit</p> <p>The service should have a rolling programme of audit, including:</p> <p>a. Audit of implementation of clinical guidelines (QS HN-500s).</p> <p>b. Participation in agreed network-wide audits.</p>	N	There was no rolling programme of audit in place and the expected audit had not been carried out.	N	There was no rolling programme of audit in place and the expected audit had not been carried out.
HN-706 SHC	<p>Research</p> <p>The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.</p>	N	The service did not participate in research relating to the care of patients with haemoglobin disorders.	N	The service did not participate in research relating to the care of patients with haemoglobin disorders.
HN-707 SHC	<p>Trans-Cranial Doppler Quality Assurance (Paediatric Services Only)</p> <p>The service should monitor and review at least annually:</p> <p>a. Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-210 and HN-512)</p> <p>b. Results of internal quality assurance systems (QS HN-512)</p> <p>c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established)</p> <p>d. Results of 'fail-safe' arrangements and any action required</p>	N/A		N/A	Trans Cranial Doppler scanning was provided on an outreach basis by Newcastle Upon Tyne Hospitals NHS Foundation Trust.

South Tees Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-798 All	<p>Review and Learning</p> <p>The service should have appropriate multi-disciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, audit results, incidents and 'near misses'. This should include:</p> <ul style="list-style-type: none"> a. Review of any patient with a serious adverse event or who died b. Review of any patients requiring admission to a critical care facility 	Y		Y	
HN-799 All	<p>Document Control</p> <p>All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.</p>	Y		Y	

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SPECIALIST SERVICES FOR PEOPLE WITH HAEMOGLOBIN DISORDERS – THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-101 All	<p>Haemoglobin Disorder Service Information</p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ul style="list-style-type: none"> a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: <ul style="list-style-type: none"> i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent) v. Give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns vi. Get involved in improving services (QS HN-199) 	Y		Y	

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-102 All	<p>Information about Haemoglobin Disorders</p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> a. A description of the condition (SC or T), how it might affect the individual and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Splenic palpation and Trans-Cranial Doppler scanning (children only) e. Transfusion and iron chelation f. Possible complications, including priapism and complications during pregnancy g. Health promotion, including: <ol style="list-style-type: none"> i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Stopping smoking h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions 	Y		Y	

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-103 All	<p>Information for Primary Health Care Team</p> <p>Written information should be sent to the patient's primary health care team covering available local services and</p> <ol style="list-style-type: none"> a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b. Side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on hydroxycarbamide and iron chelation therapy (if being prescribed by GPs). d. Immunisations e. Indications and arrangements for seeking advice from the specialist service 	Y		Y	
HN-104 All	<p>Care Plan</p> <p>All patients should be offered:</p> <ol style="list-style-type: none"> a. An individual care plan or written summary of their annual review including: <ol style="list-style-type: none"> i. Information about their condition ii. Plan for management in the Emergency Department iii. Planned acute and long-term management of their condition, including medication iv. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed <p>The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).</p>	Y	<p>The patient passport contained comprehensive information for patients with haemoglobinopathies and was available both electronically and within the notes. A hard copy was given to each patient. Clinic letters were given to each patient.</p> <p>See main report.</p>	Y	<p>The patient passport contained comprehensive information for patients with haemoglobinopathies and was available both electronically and within the notes. A hard copy was given to each patient. Clinic letters were given to each patient.</p> <p>See main report.</p>

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-105 All	<p>School Care Plan (Paediatric Services Only)</p> <p>A School Care Plan should be agreed for each child or young person covering, at least:</p> <ol style="list-style-type: none"> School attended Medication, including arrangements for giving / supervising medication by school staff What to do in an emergency whilst in school Arrangements for liaison with the school 	N/A		Y	
HN-106 SHC (A-LHT)	<p>Transition to Adult Services</p> <p>Young people transferring to the care of adult services should be offered written information covering at least:</p> <ol style="list-style-type: none"> Their involvement in the decision about transfer and, with their agreement, involvement of their family or carer A joint meeting between children's and adult services to plan the transfer A named coordinator for the transfer of care A preparation period prior to transfer Arrangements for monitoring during the time immediately after transfer 	Y	<p>The same clinical team cared for both paediatric patients and adults.</p> <p>See main report.</p>	Y	<p>The same clinical team cared for both paediatric patients and adults. For the size of the service transition was adequately addressed.</p> <p>See main report.</p>

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-107 SHC	<p>Information about Trans-Cranial Doppler Ultrasound</p> <p>Written information should be offered to patients and their carers covering:</p> <ol style="list-style-type: none"> Reason for the scan and information about the procedure Details of where and when the scan will take place and how to change an appointment Staff who will be present and will perform the scan Any side effects Informing staff if the child is unwell or has been unwell in the last week How, when and by whom results will be communicated 	N/A		Y	A good information sheet was in place.
HN-199 All	<p>Involving Patients and Carers</p> <p>The service's involvement of patients and carers should include:</p> <ol style="list-style-type: none"> Mechanisms for receiving feedback from patients and carers An annual patient survey (or equivalent) Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service Examples of changes made as a result of feedback and involvement of patients and carers 	N	<p>Mechanisms for receiving feedback from patient's and carers were not yet embedded in the service although a patient survey was being undertaken at the time of the review.</p> <p>There was no evidence of changes made as a result of feedback.</p>	N	<p>Mechanisms for receiving feedback from patient's and carers were not yet embedded in the service although a patient survey was being undertaken at the time of the review.</p> <p>There was no evidence of changes made as a result of feedback.</p>

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-201 All	<p>Lead Consultant</p> <p>A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have session/s identified for this role within their job plan.</p>	Y		N	An adult haematologist was the lead for the service with some dedicated job plan time for the care of children and young people.
HN-202 All	<p>Cover for Lead Consultant</p> <p>Cover for absences of the lead consultant should be available. In SHCs this should be a named deputy within the SHC with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHC. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHC advice and support.</p>	Y	Cover was available via three haematologists with haemoglobinopathy experience.	N	Cover for the lead adult consultant was available. See above.

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-203 All	<p>Lead Nurse</p> <p>A lead nurse should have appropriate time available for their leadership role and:</p> <ul style="list-style-type: none"> a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. RCN competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only) 	N	The job description did not cover all aspects of this Quality Standard.	N	The job description did not cover all aspects of this Quality Standard.

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-204 All	<p>Staffing Levels and Competences</p> <p>The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including:</p> <ol style="list-style-type: none"> Medical staffing for clinics and regular reviews Medical staffing for emergency care, in and out of hours Nurse staffing on the ward and day unit Clinical nurse specialist/s with responsibility for the acute service Clinical nurse specialist/s with responsibility for the community service Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion. Clinical or health psychologist with an interest in haemoglobin disorders <p>Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT).</p> <p>Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders.</p> <p>Cover for absences should be available.</p>	N	Points 'f' and 'g' were not met.	N	Points 'a', 'd', and 'g' were not met.
HN-205 All	<p>Competences and Training</p> <p>A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders (QS HN-204).</p>	N	There was no documented evidence of training for any staff involved in haemoglobinopathy care.	N	There was no documented evidence of training for any staff involved in haemoglobinopathy care.

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-206 SHC	Specialist Advice During normal working hours a consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients.	Y		Y	
HN-207 All	Training for Emergency Department Staff The service should offer regular training in the care of patients with haemoglobin disorders to: a. Clinical staff in the Emergency Department b. Nursing staff on general wards to which patients with haemoglobin disorders may be admitted	Y	The clinical lead provided teaching to medical and Emergency Department trainees.	Y	The clinical lead provided teaching to medical and Emergency Department trainees.
HN-208 All	Safeguarding Training All staff caring for people with haemoglobinopathies should have undertaken appropriate training in: a. Safeguarding children and/or vulnerable adults (as applicable) b. Equality and diversity	Y		Y	
HN-209 SHC	Doctors in Training The service should ensure that doctors in training have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	N	Haematology registrars had limited opportunity to gain competences in the care of people with haemoglobin disorders. A previous arrangement within the region whereby trainees were able to gain relevant experience in a larger centre was no longer in place.	N	Haematology registrars had limited opportunity to gain competences in the care of people with haemoglobin disorders. A previous arrangement within the region whereby trainees were able to gain relevant experience in a larger centre was no longer in place.

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-210 SHC	<p>Trans-Cranial Doppler Ultrasound Competences (Paediatric Services Only)</p> <p>Sufficient staff with appropriate competences for Trans-Cranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.</p>	N/A		Y	
HN-299 All	<p>Administrative, Clerical and Data Collection Support</p> <p>Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.</p>	Y		Y	
HN-301 All	<p>Support Services</p> <p>Timely access to the following services should be available:</p> <ul style="list-style-type: none"> j. Psychologist with an interest in haemoglobinopathies k. Social worker l. Leg ulcer service m. Play specialist (children's services only) n. Chronic pain team o. Dietetics p. Physiotherapy q. Occupational therapy r. Mental health services (adult and CAMHS) <p>In Specialist Centre's these staff should have specific competences in the care of people with haemoglobin disorders and sufficient time for patient care and for attending multi-disciplinary meetings (HN-602) if required.</p>	N	Access to generic Trust psychology services was available.	N	Access to generic Trust psychology services was available.

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-302 SHC	<p>Specialist On-site Support</p> <p>Access to the following specialist staff and services should be available on the same hospital site as the specialist team:</p> <ul style="list-style-type: none"> g. Manual exchange transfusion (24/7) h. Acute pain team including specialist monitoring of patients with complex analgesia needs i. Consultant obstetrician with an interest in care of people with haemoglobin disorders j. Respiratory physician with interest in chronic sickle lung disease k. High dependency care, including non-invasive ventilation l. Intensive care (note 2) 	Y		Y	

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-303 SHC A-LHT	<p>Specialist Services - Network</p> <p>Access to the following specialist staff and services should be available:</p> <ul style="list-style-type: none"> a. Erythrocytapheresis b. Pulmonary hypertension team c. Fertility, contraception and sexual health services, including pre-implantation genetic diagnosis d. Consultant cardiologist e. Consultant endocrinologist f. Consultant hepatologist g. Consultant neurologist h. Consultant ophthalmologist i. Consultant nephrologist j. Consultant urologist with expertise in managing priapism and erectile dysfunction k. Orthopaedic service l. Specialist imaging, including <ul style="list-style-type: none"> i. MRI tissue iron quantification of the heart and liver ii. Trans-Cranial Doppler ultrasonography (children) m. Neuropsychologist n. DNA studies o. Polysomnography and ENT surgery p. Bone marrow transplantation services <p>Specialist services should have an appropriate level of specialist expertise in the care of people with haemoglobin disorders.</p>	Y	<p>There was no on site access to automated red cell exchange. Patients were referred to other larger centres as appropriate.</p> <p>A T2* (Magnetic Resonance Imaging) service was available. R2 MRI was delivered in South Tees.</p> <p>Joint orthopaedics clinics were in place.</p>	Y	<p>There was no on site access to automated red cell exchange. Patients were referred to other larger centres as appropriate.</p> <p>A T2* (Magnetic Resonance Imaging) service was available. R2 MRI was delivered in South Tees.</p> <p>Joint orthopaedics clinics were in place.</p>

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-304 All	Laboratory Services UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y		Y	
HN-401 All	Facilities Available The environment and facilities in phlebotomy, out-patient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child friendly environment, including toys and books / magazines for children and young people of all ages.	N	Patient with complex needs were not admitted to the site where the haemoglobinopathy team was based. See main report.	N	There was limited capacity to review patients attending with acute complications. See main report.
HN-402 All	Facilities for Out of Hours Care Facilities should be available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	N	Facilities for out of hours transfusion, phlebotomy and out-patients care were not available.	N	Facilities for out of hours transfusion, phlebotomy and out-patients care were not available.

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-501 SHC A-LHT	<p>Transition Guidelines</p> <p>Network-agreed guidelines on transition to adult care should be in use covering at least:</p> <ul style="list-style-type: none"> a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams 	Y	<p>A guideline was in place but was not followed in practice.</p> <p>See main report.</p>	Y	<p>A guideline was in place but was not followed in practice.</p> <p>See main report.</p>
HN-502 All	<p>Monitoring Checklists</p> <p>Checklists should be in use for:</p> <ul style="list-style-type: none"> a. First out-patient appointment (SHC & A-LHT only) b. Routine monitoring c. Annual review (SHC & A-LHT only) <p>Use of the checklists should cover both clinical practice and information for patients and families.</p>	N	<p>First appointment checklists were not yet in use.</p>	N	<p>First appointment checklists were not yet in use.</p>

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-503 LHT	<p>Clinical Guidelines: LHT Management and Referral</p> <p>Network-agreed guidelines on routine out-patient monitoring and management between annual reviews should be in use which specify the indications for telephone advice, early referral and immediate transfer to the Specialist Centre.</p>	N/A		N	Guidelines were not yet in place.
HN-504 All	<p>Transfusion Guidelines</p> <p>Transfusion guidelines should be in use covering:</p> <ol style="list-style-type: none"> Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion Offering access to exchange transfusion to patients on long-term transfusions Protocol for carrying out an exchange transfusion Hospital transfusion policy Investigations and vaccinations prior to first transfusion Review by specialist nurse or doctor prior to transfusion to ensure each transfusion is appropriate. Areas where transfusions will usually be given Recommended number of cannulation attempts 	N	<p>The guideline contained insufficient details.</p> <p>See main report.</p>	N	<p>The guideline contained insufficient details.</p> <p>See main report.</p>

	The Newcastle upon Tyne Hospitals NHS Foundation Trust	Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-505 All	<p>Chelation Therapy</p> <p>Network-agreed clinical guidelines on chelation therapy should be in use covering:</p> <ol style="list-style-type: none"> Indications for chelation therapy Choice of chelation drug/s, dosage and dosage adjustment Monitoring of haemoglobin levels prior to transfusion Management and monitoring of iron overload, including management of chelator side effects Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT/SHC. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible. 	Y	<p>There was a guideline in place but it would benefit from inclusion of further detail.</p> <p>See main report.</p>	Y	<p>There was a guideline in place but it would benefit from inclusion of further detail.</p> <p>See main report.</p>

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-506 All	<p>Clinical Guidelines: Acute Complications</p> <p>Network-agreed clinical guidelines on the management of acute complications should be in use covering at least:</p> <p>For patients with sickle cell disease:</p> <ol style="list-style-type: none"> Acute pain Fever, infection and overwhelming sepsis Acute chest syndrome Abdominal pain and jaundice Acute anaemia Stroke and other acute neurological events Priapism Acute renal failure Haematuria Acute changes in vision Acute splenic sequestration (children only) <p>For patients with thalassaemia:</p> <ol style="list-style-type: none"> Fever, infection and overwhelming sepsis Cardiac, hepatic or endocrine decompensation 	N	<p>Guidelines for thalassaemia were not in place.</p> <p>Guidelines did not reflect clinical practice in most centres and some required reorganisation and division into age-related sections.</p>	N	<p>Guideline for thalassaemia were not in place.</p> <p>Guidelines did not reflect clinical practice in most centres and some required reorganisation and division into age-related sections.</p>
HN-507 All	<p>Specialist Management Guidelines</p> <p>Network-agreed clinical guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia:</p> <ol style="list-style-type: none"> During anaesthesia and surgery Who are pregnant Receiving hydroxycarbamide therapy 	N	<p>Some national guidance was in use but had not yet been localised.</p> <p>Hydroxycarbamide guidance required further detail.</p>	N	<p>Some national guidance was in use but had not yet been localised.</p> <p>Hydroxycarbamide guidance required further detail.</p>

	The Newcastle upon Tyne Hospitals NHS Foundation Trust	Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-508 All	<p>Clinical Guidelines: Chronic complications</p> <p>Network-agreed clinical guidelines on the management of chronic complications should be in use covering at least:</p> <ul style="list-style-type: none"> a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain i. Liver disease j. Growth delay / delayed puberty (children only) k. Enuresis (children only) 	N	Guidelines were not yet in place.	N	Guidelines were not yet in place.
HN-509 SHC	<p>Referral for Consideration of Bone Marrow Transplantation</p> <p>Guidelines for referral for consideration of bone marrow transplantation should be in use.</p>	N	Guidelines were not yet in place.	N	Guidelines were not yet in place.
HN-510 All	<p>Thalassaemia Intermedia</p> <p>Network-agreed clinical guidelines for the management of thalassaemia intermedia should be in use, covering:</p> <ul style="list-style-type: none"> a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy 	N	Guidelines for thalassaemia were not in place.	N	Guidelines for thalassaemia were not in place.

	The Newcastle upon Tyne Hospitals NHS Foundation Trust	Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-511 All	<p>Clinical Guideline Availability</p> <p>Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, clinic and ward areas.</p>	N	Guidelines for the management of chronic complications were not yet in place.	N	Guidelines for the management of chronic complications were not yet in place.

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-512 SHC	<p>Trans-Cranial Doppler Ultrasound Guidelines (Paediatric Services Only)</p> <p>Guidelines on Trans-Cranial Doppler ultrasound should be in use covering at least:</p> <ol style="list-style-type: none"> Identification of ultrasound equipment and maintenance arrangements Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-210) Arrangements for supervision of doctors in training performing Trans-Cranial Doppler ultrasound Ensuring all patients are given relevant information (QS HN-107) Use of an imaging consent procedure Guidelines on cleaning ultrasound probes Arrangements for recording and storing images and ensuring availability of images for subsequent review Reporting format, including whether mode performed was imaging or non-imaging Arrangements for documentation and communication of results Internal systems to assure quality, accuracy and verification of results Participation in the National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler ultrasound (when established) or local peer review arrangements (until NQAS established) 	N/A		Y	

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-601 All	<p>Service Organisation</p> <p>A service organisation policy should be in use covering arrangements for:</p> <ul style="list-style-type: none"> a. 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by a specialist SHC (SHC only) b. Ensuring all patients are reviewed by a senior haematology decision-maker within 12 hours of acute admission c. Patient discussion at multi-disciplinary team meetings (QS HN-602) d. Out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population e. Arrangements for liaison with community paediatricians and with schools (children's services only) f. 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated g. Follow up of patients who do not attend h. Transfer of care of patients who move to another area, including communication with all SHC, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHC, LHT and community services who will be taking over their care. i. Accessing specialist advice (QS HN-206) j. Two-way communication of patient information between SHC and LHTs k. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together 	N	'Fail-safe' arrangements were covered in the operational policy but not all information required by the standard was included.	N	'Fail-safe' arrangements were covered in the operational policy but not all information required by the standard was included.

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-602 All	Multi-Disciplinary Meetings Multi-disciplinary team meetings should be held regularly involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, other members of the service team (QS HN-204) and representatives of support services (QS HN-301).	N	Multi-disciplinary meetings, as envisaged by this Quality Standard, were not yet in place.	N	Multi-disciplinary meetings, as envisaged by this Quality Standard, were not yet in place.
HN-603 All	Service Level Agreement with Community Services A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	N/A		N/A	
HN-604 All	Network Review and Learning Meetings At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).	Y		Y	
HN-605 SHC	Neonatal screening programme review meetings The SHC should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results (HN-704), identify issues of mutual concern and agree action.	N/A		Y	Twice yearly meetings were in place.

	The Newcastle upon Tyne Hospitals NHS Foundation Trust	Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-701 SHC	<p>Data Collection</p> <p>Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events.</p>	Y	Data were input by the lead consultant.	Y	Data were input by the lead consultant.
HN-702 All	<p>Annual Data Collection - Activity</p> <p>The service should monitor on an annual basis:</p> <ol style="list-style-type: none"> Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances Length of in-patient stays Re-admission rate 'Did not attend' rate for out-patient appointments 	N	Data were not monitored.	N	Data were not monitored.

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-703 SHC	<p>Annual Data Collection – Network Patient Data</p> <p>The SHC should monitor on an annual basis, separately for sickle cell disease and thalassaemia:</p> <ol style="list-style-type: none"> a. Number of patients under active care in the network at the start of each year b. Number of new patients accepted by network services during the course of the year: <ol style="list-style-type: none"> i. Births ii. Transferred from another service iii. Moved into the UK c. For babies identified by the screening service: <ol style="list-style-type: none"> i. Date seen in clinic ii. Date offered and prescribed penicillin d. Number of network patients who had their comprehensive annual review undertaken and documented in the last year e. Number of network patients on long-term transfusion f. Number of network patients on chelation therapy g. Number of network patients on hydroxycarbamide h. Number of paediatric patients (HbSS and HbSB) who have had Trans-Cranial Doppler ultrasonography undertaken within the last year <ol style="list-style-type: none"> i. Number of pregnancies in network patients j. Number of network patients whose care was transferred to another service during the year k. Number of network patients who died during the year l. Number of network patients lost to follow up during the year 	N		N	

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-704 All	<p>Audit Clinical audits covering the following areas should have been undertaken within the last two years:</p> <p>Achievement of screening follow-up standards:</p> <ul style="list-style-type: none"> a. At least 90% of infants with a positive screening result attend a local clinic by three months of age b. At least 90% of cases of HbSS and HbSC have confirmation of result documented in clinical notes by six months of age c. Less than 10% of cases on registers lost to follow up within the past year <p>For patients with sickle cell disease:</p> <ul style="list-style-type: none"> d. Proportion of patients with recommended immunisations up to date e. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required f. Compliance with NICE Clinical Guideline on the management of acute pain, including proportion of patients attending in acute pain who received first analgesia within 30 minutes of arrival, and achieved adequate pain control within two hours of arrival g. Availability of extended red cell phenotype in all patients h. Proportion of children: <ul style="list-style-type: none"> i. at risk of stroke who have been offered and/or are on long-term transfusion programmes ii. who have had a stroke <p>For patients with thalassaemia:</p> <ul style="list-style-type: none"> i. Evidence of effective monitoring of iron overload, including imaging (QS HN-505) j. Proportion of patients who have developed new iron-related complications in the preceding 12 months <p>All patients:</p> <ul style="list-style-type: none"> k. Waiting times for transfusion 	N	The expected audits had not yet been undertaken.	N	The expected audits had not yet been undertaken.

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-705 All	<p>Guidelines Audit</p> <p>The service should have a rolling programme of audit, including:</p> <ul style="list-style-type: none"> a. Audit of implementation of clinical guidelines (QS HN-500s). b. Participation in agreed network-wide audits. 	N	A rolling programme of audit was not yet in place.	N	A rolling programme of audit was not yet in place.
HN-706 SHC	<p>Research</p> <p>The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.</p>	Y		Y	
HN-707 SHC	<p>Trans-Cranial Doppler Quality Assurance (Paediatric Services Only)</p> <p>The service should monitor and review at least annually:</p> <ul style="list-style-type: none"> a. Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-210 and HN-512) b. Results of internal quality assurance systems (QS HN-512) c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established) d. Results of 'fail-safe' arrangements and any action required 	N/A		N	At the time of the visit evidence for this Quality Standard was not seen by the review visit team.

The Newcastle upon Tyne Hospitals NHS Foundation Trust		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-798 All	<p>Review and Learning</p> <p>The service should have appropriate multi-disciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, audit results, incidents and 'near misses'. This should include:</p> <ol style="list-style-type: none"> a. Review of any patient with a serious adverse event or who died b. Review of any patients requiring admission to a critical care facility 	Y		Y	
HN-799 All	<p>Document Control</p> <p>All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.</p>	Y		Y	

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HAEMOGLOBIN DISORDERS CLINICAL NETWORK

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-199	<p>Involving Patients and Carers</p> <p>The network should have mechanisms for involving patients and their carers from all services in the work of the network.</p>	N	Network mechanisms were not yet in place.	N	Network mechanisms were not yet in place.
HY-201	<p>Network Leads</p> <p>The network should have a nominated:</p> <ul style="list-style-type: none"> a. Lead consultant and deputy b. Lead specialist nurse for acute care c. Lead specialist nurse for community services d. Lead manager e. Lead for service improvement f. Lead for audit g. Lead commissioner 	Y		Y	
HY-202	<p>Education and Training</p> <p>The network should have agreed a programme of education and training to help services achieve compliance with Qs HN-204 and HN-205.</p>	N	There was no programme of education and training in place.	N	There was no programme of education and training in place.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-501	<p>Transition Guidelines</p> <p>Network guidelines on transition to adult care should have been agreed covering:</p> <ul style="list-style-type: none"> a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. Communication of clinical information from paediatric to adult services e. Arrangements for monitoring during the time immediately after transfer to adult care f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable) <p>Guidelines should be explicit about transition directly to any accredited LHTs.</p>	N	Network agreed guidelines were not yet in place.	N	Network agreed guidelines were not yet in place.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-502	<p>Clinical Guidelines</p> <p>Network guidelines should have been agreed covering:</p> <ul style="list-style-type: none"> a. Annual review (QS HN-502) b. Routine monitoring (QS HN-503) c. Transfusion (QS HN-504) d. Chelation therapy, including guidelines for shared care with general practice (QS HN-505) e. Management of acute complications (QS HN-506), including indications for referral to specialist services (QS HN-303) f. Management of chronic complications (QS HN-508), including indications for referral to specialist services (QS HN-303) g. Specialist management (QS HN-507) h. Thalassaemia intermedia (QS HN-510) <p>Guidelines should be explicit about any accredited LHTs which may take responsibility for annual reviews or any other aspect of care usually provided by SHCs.</p>	N	Network agreed guidelines were not yet in place.	N	Network agreed guidelines were not yet in place.
HY-701	<p>Ongoing Monitoring</p> <p>The network should monitor on a regular basis:</p> <ul style="list-style-type: none"> a. Submission of data on all patients to the National Haemoglobinopathy Registry (QS HN-701) b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year. 	N	Network agreed guidelines were not yet in place.	N	Network agreed guidelines were not yet in place.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-702	<p>Audit</p> <p>The network should have an agreed programme of audit and review covering network-wide achievement of Qs HN-703, HN-704, HN-705 and HN-707.</p>	N	An agreed audit plan was not yet in place.	N	An agreed audit plan was not yet in place.
HY-703	<p>Research</p> <p>The network should have agreed:</p> <ol style="list-style-type: none"> A policy on access to research relating to the care of patients with haemoglobin disorders A list of research trials available to all patients within the network. 	N	There was no policy in place for research.	N	There was no policy in place for research.
HY-798	<p>Network Review and Learning</p> <p>The SHC should meet at least twice a year with its referring LHT teams to:</p> <ol style="list-style-type: none"> Identify any changes needed to network-wide policies, procedures and guidelines Review results of audits undertaken and agree action plans Review and agree learning from any positive feedback or complaints involving liaison between teams Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams Consider the content of future training and awareness programmes (QS HY-202) 	Y		Y	

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COMMISSIONING

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HZ-601	<p>Commissioning of Services</p> <p>Commissioners should have agreed the configuration of clinical networks based on the expected referral pattern to each SHC and LHT and, within each network, the configuration and location of services for people with haemoglobin disorders across each network, taking into account the type of patient (sickle cell and/or thalassaemia) who will be treated by each team, in particular:</p> <ul style="list-style-type: none"> a. Designated SHC/s for the care of people with with sickle cell disease b. Designated SHC/s for the care of adults with thalassaemia c. Any agreements for delegation of annual reviews to accredited LHTs for care of people with sickle cell disease or thalassaemia d. Other LHTs/Linked providers for care of adults with sickle cell disease or thalassaemia e. Community care providers 	N	Commissioners had not yet agreed the configuration of clinical networks for the region.	N	Commissioners had not yet agreed the configuration of clinical networks for the region.
HZ-701	<p>Clinical Quality Review Meetings</p> <p>Commissioners should regularly review the quality of care provided by:</p> <ul style="list-style-type: none"> a. Each service, in particular QS HN-703 b. Each network, in particular, achievement of QS HY-702 and QS HY-798. c. Service and network achievement of relevant QSs 	N	Clinical quality review meetings were not yet in place.	N	Clinical quality review meetings were not yet in place.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HZ-798	<p>Network Review and Learning</p> <p>Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.</p>	N	Network review and learning meetings were not yet in place.	N	Network review and learning meetings were not yet in place.

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