MLCSU Clinical

NHS
Midlands and Lancashire
Commissioning Support Unit

Health Services for People with Haemoglobin Disorders

Liverpool University Hospitals NHS Foundation Trust

The Royal Liverpool University Hospital

Visit date: 13th March 2024

Report date: 11th July 2024

Contents

Introduction

This report presents the findings of the review of Liverpool University Hospitals NHS Foundation Trust that took place on 13th March 2024. The purpose of the visit was to review compliance with the Health Services for People with Haemoglobin Disorders Quality Standards Version 5.1, November 2021 which were developed by the UK Forum for Haemoglobin Disorders (UKFHD). The peer review programme and visit was organised by the Nursing and Urgent Care Team (NUCT) at the Midlands and Lancashire Commissioning Support Unit (MLCSU). The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

- Specialist Haemoglobinopathy Team
- Local Haemoglobinopathy Team (or Linked Provider)

A comprehensive peer review of Local Haemoglobinopathy Teams (LHT) against the Local Haemoglobinopathy Team Quality Standards were not part of the 2024-2026 programme, however Haemoglobinopathy Coordinating Centres were given the option to request a review visit for any of their Local Haemoglobinopathy Teams in their review visit programme.

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. Any immediate risks identified will include the Trust and UKFHD/MLSCU response to any actions taken to mitigate against the risk. Appendix 1 lists the visiting team that reviewed the services in Liverpool University Hospitals NHS Foundation Trust health economy. Appendix 2 contains the 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:

- Liverpool University Hospitals NHS Foundation Trust
- NHS England – North West
- NHS Cheshire and Merseyside Integrated Care Board

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, including commissioners of primary care. The lead commissioners in relation to this report is NHS England North West and NHS Cheshire and Merseyside Integrated Care Board.

About the UKFHD and MLCSU

The UK Forum on Haemoglobin Disorders (UKFHD) is a multi-disciplinary group of healthcare professionals interested in all aspects of sickle cell disease, thalassaemia, and related conditions. The Forum is now a recognised and respected organisation involved in formulating national policy for screening and management of these conditions. The UKFHD aims to ensure equal access of optimal care for all individuals living with an inherited haemoglobin disorder. The mission of the UKFHD is to, advocate and influence policy, promote and review best practice, share ideas, and advise on research, educate health professionals, and support education

of patients, whilst influencing and advocating on equitable prevention programmes for sickle cell and thalassaemia disorders.

The Midlands and Lancashire Commissioning Support Unit (MLCSU) Nursing and Urgent Care Team (NUCT) is a trusted partner for specialist, independent, clinical, and analytical guidance on a regional, national, and international scale. Our team has significant experience in developing, facilitating, and delivering peer review programmes.

More detail about the work of the UKFHD and the MLCSU is available at https://haemoglobin.org.uk/ and https://www.midlandsandlancashirecsu.nhs.uk/our-expertise/nursing-and-urgent-care/

Acknowledgements

The UKFHD and MLCSU would like to thank the staff and service users and carers of Liverpool University Hospital health economy for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks, are also due to the visiting team and their employing organisations for the time and expertise they contributed to this review.

Return to Index

Review visit findings

Liverpool University Hospitals NHS Foundation Trust

Trust-wide General comments

Liverpool University Hospitals Foundation Trust (LUFT) and Alder Hey (Alder Hey) NHS Foundation Trust were designated as a joint Specialist Haemoglobinopathies Team (SHT) in April 2019. SHT commissioning sits with LUFT and recharged to Alder Hey. Both report into the commissioner in parallel.

LUFT was created in October 2019 following the merger acquisition (referred to as merger) between Aintree University Hospital NHS Foundation Trust and the Royal Liverpool and Broadgreen University Hospitals NHS Trust, including Liverpool University Dental Hospital. The merger created one of the largest university teaching Trusts in the country, with nearly 14,000 staff and serving a core population of around 630,000 people across Merseyside, as well as providing a range of highly specialist services to a catchment area of more than two million people in the Northwest region and beyond. Liverpool has a large student population of around 75,000.

The Specialist Haemoglobinopathy Team is based in the Royal Liverpool University Hospital (RLUH) which is based in the city centre. The area covered includes Merseyside, North Cheshire, and North Wales and the Isle of Man.

The hospital has a large and extremely busy Emergency department, large ICU and HDU complex >50 beds. The HPLC laboratory is situated on site. Most support services (nephrology, ophthalmology etc.) are based on site with Maternity services based at the Liverpool Women's Hospital which is 1 mile from main hospital. Haemato-oncology is provided at the co-located Clatterbridge Centre with benign haematology based at the RLUH.

The current adult team consists of a Lead and Deputy Haematology Consultant, 2 x clinical nurse specialist (1.3WTE) and haematology psychology team.

Trust-wide Good Practice

1. The Trust was planning to install a pharmacy collection locker so patients could pick up medication out of hours. Although not yet in use it was felt this flexibility would be welcomed by the patients.
2. The Trust had implemented a Digital Solution (DrDoctor) to support completion of a patient survey. The system supported text messaging which provided a link and had resulted in a 40-50% increase in response rate. The team were exploring expanding its use more widely, such as for digital pre-assessment questions. A Chat health system was used to support communication.
3. Psychology input was well embedded into routine practice with presence within the MDT meetings. The team and patients report that this expertise was readily available without undue waits.
4. The hospital had a good conference room facility where remote meetings were well supported.

Trust-wide Concern

The previous audit showed that only 24% of patients received analgesia within 30 minutes however the service clinical team felt that on completing the next audit this would have further reduced. The review team felt that the time to analgesia was influenced by several factors within the ED:

a) Poor urgent care flow has resulted in increased crowding within the ED department. The ED staff reported that they had limited physical space within the department to access and treat patients in a timely manner.

b) Timestamping of analgesia is on paper and so accuracy of this timestamp should be considered as it was not always clearly documented in the notes. There was no data for subsequent observations and assessments post analgesia available. Although the Trust used an electronic system for observations, initially these are recorded on paper.

c) ED staff use a generic log in to IT systems due to the need to access different terminals quickly with a continual change of users. The SCD and Thalassaemia guidelines, although available, were not accessible via a generic login. The ED handbook did include some high-level information and the contact details of the speciality team. Staff in the ED reported the speciality team were easily contactable and responsive.

d) The ED consultant the review team spoke to did not feel they had clear visibility of care plans or that all patients had an available care plan. Although an alert was flagged, the IT system did not support easy presentation of the care plan relying on the clinical teams to follow multiple clicks. The difficulty in navigating multiple digital systems was also reported. The ED consultant commented that this makes it difficult to '*tell SCD patients from opioid seekers*.' The patients that the visiting team spoke to on the day were aware of their care plans and had copies on their phones.

e) The visiting team heard that the ED utilised a high number of agency nurses which made education a challenge.

The review team considered that the ED flow challenges were not unique to the trust however it is recommended that there is a dedicated focus on developing better communications with the ED team. Introduction of a link consultant and link nurse champions to propagate positive attitudes and ensure regular haemoglobinopathy teaching and access to care plans is also recommended.

Trust-wide Further Considerations

1. Development of a Service Level Agreement (SLA) between Alder Hey and LUFT to formalise provision of the shared SHT service.

2. Patients with haemoglobinopathy disorders did not have easy access to social, immigration or benefits advice which resulted in clinical staff spending a considerable amount of time supporting patients and their families with welfare issues. It was also highlighted that signposting was difficult to wider social services due to council funding cuts. Earmarked time with Citizen's Advice Bureau or equivalent possibly co-located with the main haemoglobinopathy clinic once a month, might help address this need.

3. There was no community service provision other than a screening midwife. The CNSs help fulfil required community care, however the sustainability of this with the growing numbers should be considered.

4. The visiting team noted that there was little information for patients on SCD and thalassaemia on the walls in the ward. The Trust does not allow posters on the walls as policy, however the addition of some notice boards in haematology areas would support information to be displayed without detriment to the paintwork. The RLUH Executive the reviewed team spoke to during the visit confirmed that this issue would be addressed with dedicated noticeboards.

Views of Service Users and Carers

Support Group available for patients and carers	Y/N
Sickle Cell Disease – Adults	N
Thalassaemia – Adults	N

During the visit the visiting team met with 9 service users and carers, all with sickle cell disease.

The views of the users were very positive and are documented in the adult specialist haemoglobinopathy team sections. The review team would like to thank them for their openness and willingness to share their experiences.

Return to Index

Specialist Haemoglobinopathy Team (Adult Services): Royal Liverpool University Hospital

General Comments and Achievement

This was an experienced service with strong leadership evident throughout. The team were extremely proud of what they had achieved, and it was clear to the reviewers that the team was highly committed and enthusiastic. The reviewers felt that their response to change was commendable in sustaining the service throughout the Trust merger, a pandemic, and most recently the move to the new hospital.

There had been a significant increase in activity as the number of patients had risen by 250% in the last 3 years with a main patient concentration in the small geographical areas of Liverpool and the Wirral. The team had plans in place of how to respond to the increasing demand and were cognisant of the needs to the service users across the SHT geographical area. The SHT had 10 local haemoglobinopathy teams within their catchment, all were low prevalence areas.

The Haemoglobinopathy Team consisted of four Consultant Haematologists. There were two Clinical Nurse Specialists (1.3wte) with support from Clinical Psychology (1.4wte supporting haematology) and a 1wte Advanced Pharmacist on rotation.

LHTs representative who spoke to the reviewing teams said that the SHT managed all aspects of the patients care except in an emergency, and access to advice was straight forward with clear plans and good support from the SHT. The Trust had a 24/7 contract to provide apheresis with NHSBT which in hours was provided on a dedicated haematology day unit.

Transition commenced from the age of 13 years at Alder Hey with self-assessment questionnaires and a workbook to educate the young adult and prepare them for independence as an adult. Transfer to adult services occurred from the age of 16 years, depending on the young person's wishes and readiness for transfer. When ready for transfer children were supported with a tour of the adult facilities and familiarisation with the adult team supported by the CNS.

SPECIALIST HAEMOGLOBINOPATHY TEAM - ADULTS	
Liverpool University Hospitals NHS Foundation Trust	Linked Haemoglobinopathy Coordinating Centres (HCC)
	North West Sickle Cell HCC North of England Thalassaemia and RIA HCC
	Linked Local Haemoglobinopathy Teams (LHT)
	• Warrington • St Helens and Knowsley • Countess of Chester • Arrowe Park • Leighton • Southport • Wrexham

	• Glan Clwyd • Bangor • Nobles

PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM							
Condition		Registered patients	Active patients *[1]	Annual review **	Long-term transfusion	Eligible patients - hydroxycarbamide	In-patient admissions in last year
Sickle Cell Disease	Adults	121	114	Not stated	11	66	66
Thalassaemia and RIA	Adults	25	22	Not stated	7	N/A	2

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual PA/WTE (at time of visit)
Consultant haematologist dedicated to work with patients with haemoglobinopathies	136	4 wte Consultant Haematologists 2.6PA/week allocated to Ward Rounds/Day Unit cover from Designated Consultant of the Week. 2x 0.5PA Clinic 2x 0.375PA MDT
Clinical Nurse Specialist (CNS) for adult patients dedicated to work with patients with haemoglobinopathies	136	1.3 wte acute service
Clinical Psychologist for adult patients dedicated to work with patients with haemoglobinopathies	136	1.4 WTE for all Haematology – currently meeting needs for Haemoglobinopathy

Emergency Care

Patients experiencing mild pain could contact the haemoglobinopathy team Monday to Friday 9am to 5pm for review on Ward 1A (day ward) and advice regarding pain management at home.

Patients with moderate/severe pain were advised to attend the Emergency Department (ED). On presentation opiate analgesia could be administered in triage on access of the care plan. On the day of the visit, it was not clear that staff in ED were aware of this or how to access it. The patients the review team spoke to on the day of the visit had these plans on their phones.

[1] ** Those who have had hospital contact in the last 12 months. **No. patients who have had an annual review in last year*

There was an Acute and Emergency Management of Sickle Cell Disease guideline available on the Trust document management system however the use of a generic log in in ED resulted in this not being readily available. The electronic Royal Liverpool Emergency Medicine Handbook contained high level guidance and the contact details for the HBO team.

The Trust use the EPRO and PEMS IT systems where flags were applied to alert clinical teams of an underlying condition, including a haemoglobin disorder.

Inpatient Care

There were 6 dedicated inpatient haematology beds situated on the 24 bedded ward 8b. The ward hosted a mixture of haematology and palliative care patients, and staff were trained and experienced in caring for patients with sickle cell disease. The ward staff were used to seeing younger people and catered for their individual needs.

A board round took place each morning attended by the consultant and CNS. The pain team reviewed all patient with patient-controlled analgesia (PCA) and there was a responsive hospital wide IV access service in hours 7 days a week.

Ward 8b had a dedicated patient sitting room with some self-catering facilities. Patient information was present however the visiting team did not see any information related to SCD or thalassaemia.

The previous audit showed that every patient was allocated to ward 8b with no outliers as the ward moved other patients to prioritise haematology beds for the HBO patients.

Day Care and Outpatients

There was a dedicated haematology ambulatory day unit on ward 1A. This was used as an assessment unit (Monday to Friday 9am to 5pm) and cared for patients requiring treatment, top up transfusion, and elective red cell exchange transfusion. Emergency 24/7 red cell exchange transfusion is supported by the NHSBT, and staff report no issues with booking patients into this service. All red cell patients came through the RLUH site, and no manual exchange was undertaken.

All patients had access to a dedicated Haematology phone line Monday to Friday 9-5pm where patients could contact the CNS for assessment and appropriate information/advice given.

Outpatient clinics ran twice a week in Outpatient Department 2. Nurse Led Clinics (with a Non-Medical Prescriber) ran on Tuesdays 1.30pm-5pm and alternate Thursdays 1.30pm-5pm. Consultant Led Clinics for complex patients ran alternate Thursdays 1.30pm-5pm.

Joint obstetric/haematology clinic ran at the Women's Hospital every 2 weeks for Cheshire and Merseyside patients and the team were about to start a nurse led obstetric haematology clinic. There were good links with the Women's Hospital team.

Ophthalmology patients could access the eye hospital which was based on the lower ground floor. Here they monitored patients and had an ambulatory care service. Urology also provided a 24/7 assessment service. Previous links with orthopaedics and renal had diminished and discussion were ongoing to re-establish these. When possible, the CNS attended the appointment with other specialties to support any required HBO care.

Community services

The was no adult community services provision. The CNS team worked hard to support patients to manage their care at home, provide informal outreach work and patients in the community often contacted the CNS for support and advise, with follow up calls arranged. Leg ulcer care was provided by the district nurses or community treatment rooms.

Although there were no plans for community service provision, the team had been involved in the development of a bid in partnership with the Liverpool School of Tropical Medicine. Using National Institute for Health and Care Research (NHIR) funding this bid was looking to establish a community hub to provide pastoral support and care. Support groups had also been involved in the development of this proposal.

Views of Service Users and Carers

The visiting team met with 9 people living with sickle cell disease. The reviewers spoke to 8 patients during the service user feedback meeting and 1 patient in the day unit. The review team did not speak to any people living with thalassaemia.

Service user and carers feedback relating to Sickle Cell care and support.

- There was very positive feedback from all the patients who really valued the care they received from the team. The patients were aware of their care plans and felt that they were appropriate to their individual needs.
- The service users had close relationships with the CNS team and felt highly reassured by this personal connection and accessibility.
- The experience of the Emergency Care Department was not as consistent. One patient waited in ED 8 hours before discharge home.
- Service users felt there was an overall lack of communication between departments. Two service users described problems when requiring an anaesthetic as other specialities did not always understand when inappropriate to do so, due to their lack of knowledge surrounding SCD.
- Two service users described the challenge of undergoing early menopause because of taking hydroxycarbamide and there was very little advice or guidance available to support them with this.
- One patient described an experience of requiring an admission when breastfeeding and that there was no consideration for this in allowing her baby with her.
- Patients commented that on being referred for specialist services, it would be good if the specialist services had greater information on SCD.
- Patient did comment that there was no support group through the service, and this is something they would want.

Good Practice

1. The visiting team were impressed to hear that the patient's uptake of the influenza vaccination had increased to between 30-40% because of vaccination being offered in clinics. There were plans to roll this out further, potentially for the covid and pneumococcal vaccinations.
2. The ambulatory day unit dedicated for non-malignant haematology care was a great facility for the patients. Led by a dedicated and passionate nursing team the unit was open 5 days a week. The CNS team attended the day unit to speak to the patients when attending which provided a personalised patient experience and support for the day unit nurses.
3. There was clear commitment from the Clinical Pharmacist who was undertaking an MSc in advanced practice with the intention of further developing this service within the team.
4. The Trust had planned to install a pharmacy collection locker so patients could pick up medication out of hours. Although not yet in use, it was felt this flexibility would be welcomed by patients.
5. The team had implemented a Digital Solution (DrDoctor) to support completion of a patient survey. The system supported text messaging which provided a link and had resulted in a 40-50% increase in response rate. The team were exploring expanding its use wider, such as for digital pre-assessment questions. A Chat health system was used to support communication.
6. Transition services were well developed with young people provided with a transition workbook at the age of 14. There were joint transition clinics with clear CNS links into Alder Hey. Once the young person reached the age of 16 acute care plans are populated and a flag placed on the system. There were formal transition clinics at RLUH to support MDT handover and patient familiarisation with the site.
7. The designated haematology ward had a patient sitting area with kitchen facilities that the visiting team felt was particularly important to prevent feelings of isolation in the single rooms. Placement of literature specific to SCD and thalassaemia would have been welcomed by the visiting team to enhance this area.
8. Joint obstetric clinics took place fortnightly at the Women's Hospital.
9. The team had been involved in the development of a bid in partnership with the Liverpool School of Tropical Medicine. Using National Institute for Health and Care Research (NHIR) funding this bid was looking to establish a community hub to provide pastoral support and care. Support groups had also been involved in the development of this proposal.
10. Psychology input was well embedded into routine practice with presence within the MDT meetings. The team and patients reported that this expertise was readily available without undue waits.
11. There was a dedicated education package for new ward starters, which included haemoglobinopathy specific information.

Immediate Risk

The review team identified no immediate risks during the visit.

Concerns

The Emergency Department and Time to Analgesia

The previous audit showed that only 24% of patients received analgesia within 30 minutes however the service clinical team felt that on completing the next audit this would have further reduced. The review team felt that the time to analgesia was influenced by several factors within the ED:

a) Poor urgent care flow has resulted in increased crowding within the ED department. The ED staff reported that they had limited physical space within the department to access and treat patients in a timely manner.

b) A haematology bed was not always timely available. The team reported that beds were available within 1 hour on a good day, but they have also had 24 hour waits for a haematology bed. The team should consider how they may support timely admission to haematology beds from ED consistently.

c) Timestamping of analgesia is on paper and so accuracy of this timestamp should be considered as it was not always clearly documented in the notes. There was no data for subsequent observations and assessments post analgesia available. Although the Trust used an electronic system for observations, initially these are recorded on paper.

d) ED staff use a generic log in to IT systems due to the need to access different terminals quickly with a continual change of users. The SCD and Thalassaemia guidelines, although available, were not accessible via a generic login. The ED handbook did include some high-level information and the contact details of the speciality team. Staff in the ED reported the speciality team were easily contactable and responsive.

e) The ED consultant the review team spoke to did not feel they had clear visibility of care plans or that all patients had care plans. Although an alert was flagged, the IT system did not support easy presentation of the care plan relying on the clinical teams to follow multiple clicks. The difficulty in navigating multiple digital systems was also reported. The ED consultant commented that this makes it difficult to '*tell SCD patients from opioid seekers*.' The patients that the visiting team spoke to on the day were aware of their care plans and had copies on their phones.

f) The visiting team heard that the ED utilised a high number of agency nurses which made education a challenge.

The review team considered that the ED flow challenges were not unique to the trust however it is recommended that there is a dedicated focus on developing better communications with the ED team. Introduction of a link consultant and link nurse champions to propagate positive attitudes and ensure regular haemoglobinopathy teaching and access to care plans is also recommended.

Further Considerations

1. Patients with hemoglobinopathy disorders did not have easy access to social, immigration or benefits advice which resulted in clinical staff spending a considerable amount of time supporting patients and their families with welfare issues. It was also highlighted that signposting was difficult to wider social services due to council funding cuts. Although the CNS able to cover this at the time of the visit the sustainability of this with the growing numbers should be considered.

2. There was no community service provision other than a screening midwife. The CNSs helped fulfil required community care however the sustainability of this with the growing numbers should be considered.

3. The visiting team noted that there was little information for patients on SCD and thalassaemia on the walls in the ward. The trust does not allow posters on the walls as policy however the addition of some notice boards in haematology areas would support information to be displayed on noticeboards without detriment to the paintwork.

4. There was limited patient engagement at support groups. The Liverpool sickle cell and thalassaemia support group was predominantly attended by children and young people with only 5-10 adults actively engaged. The patients spoken to on the day were keen to develop a support group and this should be built on for the adult support event already arranged for May 2024.

5. The visiting team heard about workforce plans that were forward thinking and innovative. The development of the pharmacy role to an Advanced Clinical Practitioner, the Quality Nurse role, and the plans for the

Principal Psychologist to undertake Neuropsychology specialist training are all commendable. The visiting team also heard about the plans to replace the soon retiring 0.7 lead CNS with 1 wte Advanced Nurse Practitioner.

However, a medical post was out to advert with previous unsuccessful recruitment, there was a data vacancy with the function being filled by the MDT, and the CNS were being supported by the wider haematology CNS team. With the growing patient numbers and fragility in some parts of the team consideration should be given to the service sustainability without additional resource, alongside the impact of the change in the nursing workforce model, and succession planning from the retirement of the lead nurse. The team should continue to explore how the pharmacy team can support hydroxycarbamide monitoring.

6. A Service Organisation Policy (SOP) for adult services at RLUH was not seen. Although the visiting team felt that the HBO team had good knowledge of the elements that would be required in a SOP, this was needed to pull together this knowledge within one document. The SOP should include clear pathways for sub-specialist review.
7. The work should continue to build nursing and medical workforce competencies and education into the electronic staff records to provide greater clarity, access, and assurance.
8. Work with IT should be progressed to allow the EPR system to pick up a list of patients that have attended ED to alert the HBO team immediately on presentation of known patients.

Commissioning

The review team had discussions with a commissioner from the NHS England Specialist Commissioning Team. Predominantly commissioning conversations took place with the HCC rather than the SHT.

The commissioner described the challenges for consistency with the recent changes to the NHSE commissioning arrangements and vacancies within the system as part of the restructure. They had a Cheshire and Merseyside ICB link lead who they are working with as they progress towards delegation.

Return to Index

Appendix 1 - Membership of Visiting Team

Visiting Team		
Annette Blackmore	Non-Malignant Haematology CNS	Cardiff and Vale UHB
Amy Webster	Adult Consultant Haematologist	University Hospitals of Leicester
Nkechi Anyanwu	Clinical Nurse Manager (Haemoglobinopathies)	Guy's & St Thomas NHS Foundation Trust
Leah Denver	Network Manager	Birmingham Women and Children's NHS Trust
Ruth Anderson	Counselling Psychologist	University College London Hospitals
Lulu Awori	Devolution, Contracts and Performance Manager	NHS England
Baaba Garvin	User representative	
Romaine Maharaj	User representative	UK Thalassaemia Society

Clinical Leads		
Sara Stuart-Smith	Consultant Adult Haematologist	King's College Hospital NHS Trust

MLCSU Team		
Kelly Bishop	Assistant Director	MLCSU

Return to Index

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 varies 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.

Percentage of Quality Standards met TBA

Service	Number of Applicable QS	Number of QS Met	% Met
Specialist Haemoglobinopathy Team (SHT) Adults	45	34	77%

Specialist Haemoglobinopathy Team for Adults with Haemoglobin Disorders

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-101	**Haemoglobin Disorder Service Information** Written information should be offered to patients and their carers, and should be easily available within patient areas, covering at least: 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 How to: i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Contact interpreter and advocacy services, Patient Advice and Liaison Service (PALS), spiritual support and Healthwatch (or equivalent) v. Give feedback on the service, including how to make a complaint vi. Get involved in improving services (QS HA-199)	**Y**	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-102	**Information about Haemoglobin Disorders** Patients and their carers should be offered written information, or written guidance on where to access information, covering at least: a. A description of their condition (SCD or Th), how it might affect them and treatment available b. Inheritance of the condition and implications for fertility c. Problems, symptoms and signs for which emergency advice should be sought d. How to manage pain at home (SCD only) e. Transfusion and iron chelation f. Possible complications g. Health promotion, including: i. Travel advice ii. Vaccination advice h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions	**N**	Written patient information covered sickle cell disorder only It was unclear from patient information that HbSS and HbSC and HbS beta thalassaemia exists – the patient information stated that you can only have sickle cell disease if you inherit the sickle gene from both parents Version control was not on all patient information documents and for some there was no author details nor date of expiry. Low oxygen levels as a cause for VOE – travel advice did not mention in flight oxygen or discussing travel plans with medical team. GP information did not contain information about contraception. No information presented about implications for fertility, partner testing etc. Travel advice does not cover inflight oxygen NHR was not mentioned Self-administered medication section did not make it clear that co-codamol and co-dydramol contain paracetamol and cannot then be taken with paracetamol. No links to national or other websites

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Planned acute and long-term management of their condition, including medication iii. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed c. The care plan and details of any changes should be copied to the patient's GP and their local team consultant (if applicable).	**Y**	The reviewers felt that the care plan was good – particularly stroke and priapism information and guidance around analgesia options and reassessment.
HA-104	**What to Do in an Emergency?** All patients should be offered information about what to do in an emergency covering at least: a. Where to go in an emergency b. Pain relief and usual baseline oxygen level, if abnormal (SCD only)	**Y**	This was well covered however could be enhanced by more thorough recording of baseline oxygen.
HA-105	**Information for Primary Health Care Team** Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD) b. Side effects of medication, including chelator agents (SCD and Th) c. Guidance for GPs on: i. Immunisations ii. Contraception and sexual health d. What to do in an emergency e. Indications and arrangements for seeking advice from the specialist service	Y	Standard well covered however could further enhance information about contraception and sexual health.
HA-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders.	**Y**	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care f. Advice for young people leaving home or studying away from home including: i. Registering with a GP ii. How to access emergency and routine care iii. How to access support from their specialist service iv. Communication with their new GP	**Y**	The reviewers were impressed by the quality of the transition guide however commented that this could be even further enhanced by the inclusion of more detailed information for young people away from home.
HA-197	**Gathering Patients' and Carers' Views** The service should gather patients' and carers' views at least every three years using: a. 'Patient Survey for Adults with a Sickle Cell Disorder' b. UKTS Survey for Adults living with Thalassaemia	**Y**	
HA-199	**Involving Patients and Carers** The service's involvement of patients and carers should include: a. Mechanisms for receiving feedback b. Mechanisms for involving patients and their carers in: i. Decisions about the organisation of the service ii. Discussion of patient experience and clinical outcomes (QS HA-797) c. Examples of changes made as a result of feedback and involvement	**N**	There were unclear mechanisms for receiving ad hoc feedback and involving patients and carers in decision about the service. However, it should be noted that there was a good liaison with CNS team and patients felt involved were keen to set up a patient support group having met as part of Peer Review, and a recent patient survey had excellent feedback and good response rates.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-201	**Lead Consultant** 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. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	**Y**	
HA-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services c. Competences in caring for people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	**Y**	
HA-204	**Medical Staffing and Competences: Clinics and Regular Reviews** The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	**Y**	
HA-205	**Medical Staffing and Competences: Unscheduled Care** 24/7 consultant and junior staffing for unscheduled care should be available. **SHTs and HCCs only:** A consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients during normal working hours. Cover for absences should be available.	**Y**	
HA-206	**Doctors in Training** If doctors in training are part of achieving QSs HA-204 or HA-205 then they should have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	**Y**	Routine SpR exposure to outpatient clinics would be desirable

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-207	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Clinical nurse specialist/s with responsibility for the acute service b. Clinical nurse specialist/s with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	**N**	c) ward nurses have some training but no competency assessment d) training received but no competencies assessment
HA-208	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders, including: a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multidisciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuropsychology Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	**Y**	
HA-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	**Y**	
HA-301	**Support Services** Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HA-602) as required: a. Social worker / benefits adviser b. Leg ulcer service c. Dietetics d. Physiotherapy (inpatient and community-based) e. Occupational therapy f. Mental health services	**N**	No social worker or benefits advisor

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-302	**Specialist Support** Access to the following specialist staff and services should be easily available: a. DNA studies b. Genetic counselling c. Sleep studies d. Diagnostic radiology e. Manual exchange transfusion (24/7) f. Automated red cell exchange transfusion (24/7) g. Pain team including specialist monitoring of patients with complex analgesia needs h. Level 2 and 3 critical care	**Y**	
HA-303	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	**Y**	
HA-304	**Urgent Care – Staff Competences** Medical and nursing staff working in Emergency Departments and admission units should have competences in urgent care of people with haemoglobin disorders.	**N**	Reviewers were concerned about the audit results for time to analgesia for sickle acute pain management (24%accessing pain relief within 30 minutes, compared with national guidelines of 100%)
HA-501	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their family or carer, paediatric and adult services, primary health care and social care in planning the transfer, including a joint meeting to plan the transfer of care 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 HCCs, SHTs and LHTs (if applicable) h. Responsibilities for giving information to the young person and their family or carer (QS HA-195)	**Y**	
HA-502	**New Patient and Annual Review Guidelines** Guidelines or templates should be in use covering: a. First outpatient appointment b. Annual review Guidelines should cover both clinical practice and information for patients and carers.	**Y**	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-505	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: i. Emergency and regular transfusion ii. Use of simple or exchange transfusion iii. Offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for: i. Manual exchange transfusion ii. Automated exchange transfusion on site or organised by another provider c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts e. Patient pathway and expected timescales for regular transfusions, including availability of out of hours services (where appropriate) and expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion f. Patient pathway for Central Venous Access Device insertion, management and removal	**Y**	
HA-506	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: 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. Self-administration of medications and infusions and encouraging patient and carer involvement in monitoring wherever possible	**Y**	The document reviewed was still in draft and requires formal sign off
HA-507	**Hydroxycarbamide and Other Disease Modifying Therapies** Guidelines on hydroxycarbamide and other disease modifying therapies should be in use covering: a. Indications for initiation b. Monitoring of compliance and clinical response, including achieving maximum tolerated dose for hydroxycarbamide c. Documenting reasons for non-compliance d. Monitoring of complications e. Indications for discontinuation	**Y**	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-508	**Non-Transfusion Dependent Thalassaemia (nTDT)** Guidelines on the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy d. Consideration of options for disease modifying therapy	**Y**	
HA-509	**Clinical Guidelines: Acute Complications** Guidelines on the management of the acute complications listed below should be in use covering at least: i. Local management ii. Indications for seeking advice from the HCC / SHT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred i. For patients with sickle cell disorder: a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision ii. For patients with thalassaemia: k. Fever, infection and overwhelming sepsis l. Cardiac, hepatic or endocrine	**Y**	To note - there is no slow release etilefrine currently available and dosages given are incorrect: *stat 50mg followed by 50mg bd should read 15mg IR followed by a further dose if required, maximum dose 30mg in 12 hours or 60mg in 24 hours.*

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-510	**Clinical Guidelines: Chronic Complications** Guidelines on the management of the chronic complications listed below should be in use covering at least: i. Local management ii. Indications for discussion at the HCC MDT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred iv. Arrangements for specialist multidisciplinary review a. Renal disease, including sickle nephropathy b. Orthopaedic problems, including the management of sickle and thalassaemia-related bone disease c. Eye problems, including sickle retinopathy and chelation-related eye disease d. Cardiological complications, including sickle cardiomyopathy and iron overload related heart disease e. Pulmonary hypertension f. Chronic respiratory disease, including sickle lung disease and obstructive sleep apnoea g. Endocrine problems, including endocrinopathies and osteoporosis h. Neurological complications, including sickle vasculopathy, other complications requiring neurology or neurosurgical input and access to interventional and neuroradiology i. Chronic pain j. Hepatobiliary disease, including sickle hepatopathy, viral liver disease and iron overload-related liver disease k. Urological complications, including priapism and erectile dysfunction l. Dental problems	**N**	f, h and k not covered No clear referral pathways for others a)-k)
HA-511	**Anaesthesia and Surgery** Guidelines should be in use covering the care of patients with sickle cell disorder and thalassaemia during anaesthesia and surgery.	**Y**	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-512	**Fertility and Pregnancy** Guidelines should be in use covering: a. Fertility, including fertility preservation, assisted conception and pre-implantation genetic diagnosis b. Care during pregnancy and delivery c. Post-partum care of the mother and baby Guidelines should cover: i. Arrangements for shared care with a consultant obstetrician with an interest in the care of people with haemoglobin disorders, including details of the service concerned ii. Arrangements for access to anaesthetists with an interest in the management of high-risk pregnancy and delivery iii. Arrangements for access to special care or neonatal intensive care, if required iv. Indications for discussion at the HCC MDT (QS HA-605) v. Arrangements for care of pregnant young women aged under 18	**Y**	
HA-599	**Clinical Guideline Availability** 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, admission units, clinic and ward areas.	**Y**	To note - ED were unable to access these as they use a generic log in which cannot access the guidelines. ED Workbook only includes acute pain in sickle cell disease guideline.
HA-601	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission b. Patient discussion at local multidisciplinary team meetings (QS HA-604) c. Follow up of patients who 'did not attend' d. Transfer of care of patients who move to another area, including communication with all haemoglobinopathy services involved with their care before the move and communication and transfer of clinical information to the HCC, SHT, LHT and community services who will be taking over their care e. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together f. Governance arrangements for providing consultations, assessments and therapeutic interventions virtually, in the home or in informal locations	**N**	No SOP was available.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-603	**Shared Care Agreement with LHTs** A written agreement should be in place with each LHT covering: a. Whether or not annual reviews are delegated to the LHT b. New patient and annual review guidelines (QS HA-502) (if annual reviews are delegated) c. LHT management and referral guidelines (QS HA-503) d. National Haemoglobinopathy Registry data collection (QS HA-701) e. Two-way communication of patient information between HCC / SHT and LHT f. Attendance at HCC business meetings (HA-607) (if applicable) g. Participation in HCC-agreed audits (HA-706)	**N**	The reviewers did not receive any evidence of a Shared Care Agreement
HA-604	**Local Multidisciplinary Meetings** MDT meetings to discuss and review patient care should be held regularly, involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, psychology staff and, when requested, representatives of support services (QS HA-301).	**Y**	
HA-606	**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**	There are no community services for adults.
HA-607S	**HCC Business Meeting Attendance (SCD)** At least one representative of the team should attend each Sickle Cell Disorder HCC Business Meeting (QS HA-702).	**N**	No Business Meeting Attendance evidenced
HA-607T	**HCC Business Meeting Attendance (Th)** At least one representative of the team should attend each Thalassaemia HCC Business Meeting (QS HA-702).	**N**	No Business Meeting Attendance evidenced
HA-701	**National Haemoglobinopathy Registry** Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies, patients lost to follow up and the number of patients who have asked to have their name removed.	**Y**	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HA-505) b. Acute admissions to inappropriate settings, including patient and clinical feedback on these admissions	**Y**	
HA-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS H-702d).	**Y**	
HA-707	**Research** The service should actively participate in HCC-agreed research trials.	**Y**	
HA-797	**Review of Patient Experience and Clinical Outcomes** The service's multidisciplinary team, with patient and carer representatives, should review at least annually: a. Achievement of Quality Dashboard metrics compared with other services b. Achievement of Patient Survey results (QS HA-197) compared with other services c. Results of audits (QS HA-705): i. Timescales and pathway for regular transfusions ii. Patients admitted to inappropriate settings Where necessary, actions to improve access, patient experience and clinical outcomes should be agreed. Implementation of these actions should be monitored.	**Y**	
HA-798	**Review and Learning** The service should have appropriate multidisciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, serious adverse events, incidents and 'near misses'.	**Y**	
HA-799	**Document Control** All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	**Y**	Requires updating in the patient information