St George's University Hospitals NHS Foundation Trust

Standard Operating Policy for the Care of Adult Patients with Sickle Cell Disease, Thalassaemia and Rare Anaemias

The Trust strives to ensure equality of opportunity for all, both as a major employer and as a provider of health care. This procedural document has been equality impact assessed to ensure fairness and consistency for all those covered by it regardless of their individual differences and the results are outlined, as required.

Profile	
Version:	*4.1*
Author:	*Dr Elizabeth Rhodes, Consultant Haematologist*
Executive/Divisional sponsor:	
Applies to:	*All staff caring for patients living with sickle cell disease, thalassaemia or rare inherited anaemias*
Date issued:	*14.2.25*
Review date:	*14.2.28 – 3 years*
Approval	
Approval person/Committee:	Dr Julia Sikorska, clinical lead for haemoglobinopathies Haemoglobinopathy Business Meeting Approval February 2025 Care Group Meeting Feb 2025
Date:	February 2025

Document History			
Version	**Date**	**Review date**	**Reason for change**
V1.0	*September 2012*		*New document*
V2.0	*April 2015*		*Review and update*
V3.0	*February 2019*		*Review and update*

Contents

Policy Gateway

Please complete the checklist and tables below to provide assurance around the policy review process.

☒ I have involved everyone who should be consulted about this policy/guidance

☒ I have identified the target audience for this policy/guidance

☒ I have completed the correct template fully and properly

☒ I have identified the correct approval route for this policy/guidance

☒ I have saved a word version of this policy/guidance for future reviews and reference

Please set out what makes you an appropriate person to conduct this review:
Consultant Haematologist in Service

Please set out the legislation, guidance and best practice you consulted for this review:
n/a

Please identify the key people you involved in reviewing this policy why, and when:
Medical, Nursing and Operational colleagues within the service -Dr Julia Sikorska, clinical lead for haemoglobinopathies -Dr Ying Ying Peng, care group lead for haematology - Joely Hampton, General Manager for haematology - Bethan Jones, Head of Nursing for haematology

Summarise the key changes you have made and why:
- Made more succinct - Updated with operational changes that have occurred over the last 5 years

Executive Summary

This Standard Operating Policy provides essential guidelines for the management and treatment of these complex conditions. It ensures consistent, evidence-based care to improve patient outcomes, reduce complications, and promote holistic support. The policy outlines clinical pathways, key interventions, and a multidisciplinary approach to patient care, emphasizing the importance of coordination between healthcare teams. The document applies to all healthcare professionals involved in the care of adult patients with these conditions and excludes pediatric care.

1. Introduction

This Standard Operating Policy outlines the best practices for the care and management of adult patients with sickle cell disease, thalassaemia, and rare anaemias at our NHS trust. It aims to provide clear, evidence-based guidance to healthcare professionals, ensuring consistent, high-quality care across all services. The policy promotes a multidisciplinary approach, emphasizing patient safety, effective treatment protocols, and improved outcomes for individuals living with these complex, long-term conditions.

2. Status and Purpose

This document is part of the Trust's haematology policies and is applicable to all staff

This document outlines the standard operating policy for providing high-quality care to adult patients with Sickle Cell Disease (SCD) and Thalassaemia at St George's and in the surrounding areas as the specialist centre.

It ensures a comprehensive and coordinated approach to outpatient, inpatient, and multidisciplinary care. The policy aligns with NHS guidance and Trust values, focusing on equity, safety, continuity, and patient-centred care with the aim to provide outstanding care every time.

3. Definitions

SCD: Sickle Cell Disease
SHT: Specialist Haemoglobinopathy Team
LHT: Local Haemoglobinopathy Team
HCC: Haemoglobinopathy Coordinating Centre
CNS: Clinical Nurse Specialist

4. Scope

This policy applies to all healthcare professionals involved in the care of adult SCD and Thalassaemia patients, including consultants, nursing staff, psychologists, allied health professionals, and administrative staff. The policy governs services including:

- Haematology outpatient services
- Emergency admission of patients
- Inpatient care and multidisciplinary rounds
- Psychological services
- Automated red cell exchange and transfusion services
- Access to novel therapies
- Multidisciplinary outpatient care
- Disease intervention and iron chelation
- Cross-service coordination and shared care arrangements

5. Roles and Responsibilities

All Staff
Adhere to the Trust's policies and guidelines for the care of patients with sickle cell disease, thalassaemia, and rare anaemias.
Provide compassionate, patient-centred care in line with best practices.
Contribute to a multidisciplinary approach and communicate effectively with the team.

Line Managers
Ensure staff are trained, supported, and compliant with policies and procedures.
Promote a culture of safety, teamwork, and continuous improvement.
Oversee staff performance and development.

Clinical Lead (Haematology)
Lead the implementation and monitoring of the care pathway.
Ensure adherence to clinical guidelines and governance standards.
Provide clinical expertise and guidance to the MDT.

Lead Nurse (Sickle Cell and Thalassaemia Specialist Nurse)
Coordinate patient care, providing education and support to patients and families.
Ensure continuity of care across services and advocate for patients' needs.
Supervise and support nursing staff in implementing best practices.

General Manager
Oversee operational delivery of services for patients with sickle cell disease, thalassaemia, and rare anaemias.
Ensure adequate resources, staffing, and facilities are available for optimal patient care.
Support the implementation of quality improvement initiatives.

Chief Executive
Ensure that the Trust is compliant with national guidelines and best practices in the care of patients with these conditions.
Promote a culture of safety, quality, and accountability across all services.
Ensure that appropriate resources are allocated for the care and management of these patients

6. Content

Profile

St George's University Hospitals NHS Foundation Trust (St George's, SGUH) is a teaching hospital with over 1000 beds and a catchment population of about 1.3 million across South-West London.

The Red Cell and Haemoglobin Disorders Unit for Adults which cares for patients with Sickle Cell & Thalassaemia is part of the Clinical Haematology Department within the Medicine & Cardiovascular Division at SGH.

There is a separate Paediatric Specialist Haemoglobinopathies Service run by the Paediatric Haematology team at St George's within the Children's and Women's division.

SGUH is the specialist centre for the South-West Thames Network comprising of the following Local Haemoglobinopathy Services (LHTs)

Trust	**Lead Clinician (as of 2024)**
St Helier's & Epsom	Caroline Ebdon
Kingston	Sangeeta Atwal
Ashford St Peters (Chertsey)	Jissan Hussain
Surrey & Sussex Healthcare (East Surrey)	Emma O'Donovan
Royal Surrey (Guildford)	Chin Neoh
Frimley Park	Kieran Burton

SGH is, in partnership with Imperial and London North-West, the Haemoglobinopathy Coordinating Centre (HCC) for West London since commissioned in April 2020.

The Adult Service at SGUH is composed of the following elements:

Multidisciplinary Clinical Team:

Consultant Lead supported by consultants with a specialist interest in haemoglobinopathies

- 3 consultants (3rd post approved February 2025)

Lead Nurse for haemoglobinopathies (from 2025)

- 1 WTE band 8a

Clinical Nurse Specialists for haemoglobinopathies

- 1.8 WTE (2 posts) band 7

Clinical Psychology (see more below)

- One Band 8a Clinical Psychologist and Service Lead (1.0 FTE)
- One Band 7 Clinical Psychologist (1.0 FTE)
- One Assistant Psychologist (0.6 WTE)

Pharmacy Support with dedicated haemoglobinopathy pharmacist from 2025

- 0.2WTE Band 8b haemoglobinopathy pharmacist

The Red Cell Pain Management and Psychology Service (RCPMPS) psychology provision includes:

- One Band 8a Clinical Psychologist and Service Lead (1.0 FTE)
- One Band 7 Clinical Psychologist (1.0 FTE)
- One Assistant Psychologist (0.6 WTE)

The service strives to provide sufficient staffing to ensure consistent support, even during staff absences.

- The RCPMPS psychology service at St George's Hospital provides specialist care to patients who receive their care at St George's hospital and partner hospitals in the region, and for patients living in Wandsworth, Merton, Sutton, Kingston, and Richmond. We also offer expert outpatient pain management input nationally, recognising that many areas may lack access to specialist services.

- RCPMPS psychologists provide psychological support across inpatient and outpatient settings.

- They attend ward round, provide one-to-one support to patients, and work closely with the haematology and nursing teams to better understand patients' presenting difficulties from a biopsychosocial perspective and develop formulations and strategies to support both patients and staff. Psychologists in the team also address safeguarding concerns as part of their holistic approach to care liaising where appropriate with additional relevant teams (e.g. adult and child safeguarding).

- In outpatient clinics, psychologists offer individual therapy sessions for patients living with red blood cell conditions, conduct annual reviews, and help connect patients to relevant external services, such as local talking therapies and mental health providers including options for external support during times of a mental health crisis when needed.

- In addition to individual support, the team runs a monthly online support group to provide a safe and accessible space where patients with sickle cell and thalassaemia can share experiences and connect with others.

The RCPMPS is a multi-disciplinary service:

- The service runs a specialist pain management clinic, co-led by a Consultant in Pain Medicine and a Clinical Psychologist.

- Joint pain self-management assessments with a Clinical Psychologist and Physiotherapist are offered as part of a multidisciplinary approach to pain management. These sessions ensure that patients are provided with a biopsychosocial approach to pain. Options for cognitive and behaviourally based self-management approaches are offered, including Pain Management Programmes (PMP) as recommended in Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK (2018). Data from the PMP has been used to evaluate the feasibility of delivering a pain management programme for adults living with sickle cell disease by the RCPMPS Highly Specialised Physiotherapist - McLoughlin, Rebecca, et al. "Evaluating the feasibility of delivering a pain management programme for adults living with sickle cell disease." *British Journal of Pain* 18.3 (2024): 257-273. The study suggests that given an adequate source of referrals, a tailored PMP for people living with sickle cell is feasible to deliver and appears acceptable and credible to participants.

- RCPMPS Psychologists actively contribute to weekly multidisciplinary team (MDT) meetings, discuss governance-related issues, and attend regular care group meetings. Their MDT contributions include providing updates on patient contact and raising safeguarding concerns. MDT discussions support referrals to neurology and neuropsychology for further assessment and follow-up where patients and/or clinicians highlight changes in cognitive functioning (e.g., attention, concentration, planning and problem-solving, memory, processing speed, and emotional regulation) and consider possible influencing factors like mood.

Day unit services – Ruth Myles Day Unit

- Top up transfusions
- Opening hours for patients 9-5 Monday – Friday
- 3 chairs
- 1 band 7, 4 x band 6, 4 band 5, 1 x band 4
- All band 5 staff and above have cannulation and transfusion competencies

Apheresis service (based on Gordon-Smith Ward)

Provides emergency and elective automated red cell exchange and plasmapheresis (as well as leukodepletion and stem cell collection) provides an outpatient elective service 6 days a week and an emergency service 7 days a week 8am-8pm

UKAS accredited biomedical sciences, haemoglobinopathy and blood transfusions laboratories as part of Southwest London Pathology (SWLP) based at St George's Hospital,

- Haemoglobinopathy lab provides antenatal services as well as diagnostic services
- HbS service available 24/7
- Staffing: Technical lead and two rotational staff
- Haemoglobinopathy lab accreditation numbers 9085 and 9745
- Re-accreditation March 2025
- Engages in UK NEQAS

Pharmacy support, based at St George's Hospital

Physiotherapy and Occupational Therapy

Support on inpatient wards, with specific expertise and experience in sickle cell including the use of incentive spirometry, respiratory support and mobilising exercises.

Community Nursing Services

Services for Sickle Cell & Thalassaemia and antenatal genetic screening covering the boroughs of Wadsworth, Merton, Kingston, Richmond and Sutton are commissioned by Central London Community Healthcare NHS Trust (CLCH)

3 x band 7 CNS

Full Circle Fund Therapy

Inpatient and outpatient sessions for patients with SCD (outpatients 6 hours / week) providing remedial massages and reiki as part of the wider holistic care available to patients

Bone Marrow Transplant Services

Hosted at St George's, JACIE accredited, experienced in non-malignant stem cell transplantation.
Matched sibling allogeneic transplants and haplo-identical transplants can be undertaken at St George's.

The service sits within the Haematology Care Group and is supported by the operational management team, including the Haemoglobinopathies Pathway Manager and Data Manager.

Wider services at St George's

There are also close working relationships with other disciplines and specialties in the hospital that our patients will use

At SGUH around 400-500 adult patients with haemoglobin disorders are registered from across the network. The services provided at SGUH include

- Emergency inpatient care for patients including critical care
- Transfusion therapy (top up and automated exchange)
- Chelation therapy
- Access to novel agents as available
- Stem Cell Transplantation (Haplo, matched sib-allogeneic transplants and matched unrelated)
- Psychology and pain services
- Outpatient MDT clinics – including medical and psychology annual reviews and treatment clinics

- Obstetrics
  - SGUH is a maternal medicine centre (MMC)
  - Sickle Cell and Transfusion Dependent Thalassaemia are classed as category C conditions where care in pregnancy is led by the MMC
  - We have a named midwife for pregnant patients who have sickle cell and thalassaemia
  - There is full multi-disciplinary work with fetal medicine, maternal medicine, obstetric physicians, obstetric anaesthetics and haematology.

- Orthopaedics
  - Close working with the complex arthroplasty unit with expertise in hip and knee replacements in patients with sickle cell disease
  - Regular MDTs as required

- Neurology
  - South West London (SWL) Neuro Sickle Multidisciplinary Team is lead by neurologists at SGUH with an interest in sickle brain conditions and is comprised of neuro-radiology, neurology, stroke physicians and haematology
  - Regular clinical MDTs
  - Sickle neurology clinics
  - Ongoing research activity

- Renal
  - Regional renal service including dialysis and transplantation
  - Regular renal-sickle MDTs

- Urology
  - Close working with colleagues specialising in priapism

- Cardiology
    - Specialist interest in cardiac iron loading in patients with both transfusion and non-transfusion related iron overload

- Critical Care
    - General ICU (GICU) 12 level 3 beds, 6 level 2
    - Cardiothoracic ITU (CTITU) 21 level 3 beds
    - Neuro ICU (NICU) 12 level 3 beds, 5 level 2 beds.
    -

Aim would be to stream patients with SCD to GICU where possible (unless clinical condition requires CTITC or NICU) and if a patient is on another unit a general ICU opinion is always available.

We have a critical care outreach team (CCOT) that can provide ward level Optiflow (High flow oxygen therapy) to 2 patients on the wards. The team is familiar with the benefit of that for patients with sickle cell disease on haematology wards.

The critical care team at St George's works collaboratively with the SWLondon critical care network and supports bringing patients with sickle cell disease to SGUH from local hospitals to ensure specialist care can be provided.

Other specialist clinical services available at SGUH include general surgery, neurosurgery, cardiology and cardiac surgery, hepatology, endocrinology and diabetes and pulmonary hypertension.

Admitting Pathways

Emergency Admission Pathway

- Patients presenting with acute complications (e.g., vaso-occlusive crises, acute chest syndrome, severe infections, or uncontrolled pain) must be admitted through the Emergency Department (ED).
- ED clinicians should liaise promptly with the on-call haematology team for assessment and initiation of care following available guidelines and individual universal care plans.
- Analgesia should be given within 30 minutes of presentation to the ED.
- Patients should be reviewed by a senior decision maker (SpR, discussions with haematology consultant or haematology consultant) within 14 hours of admission.
- Patients should be admitted to designated haematology wards (Gordon-Smith ward, Trevor Howell ward or Ruth Myles ward) for specialised care.
- There is a 24/7 haematology registrar on call and a 24/7 haematology consultant on call. When the consultant on call is a specialist in malignant haematology there is a second on call non-malignant haematology consultant available.
- Patients may also be admitted as a transfer from our local hospitals to provide specialist and critical care to patients living with sickle cell disease or thalassaemia.

When the ED bypass unit (The HyperAcute Unit, HAU) is operational the HAU SOP should be referred to.

Care During Emergency Admission

- Patients should be reviewed by a senior decision maker within 14 hours of presentation
- A multidisciplinary ward round (medical, nursing and psychology), happens routinely twice a week
- Consultant reviews at least twice a week and more as needed for acuity or complexity and for new admissions. The consultant is a haematologist with expertise in haemoglobinopathy.
- Analgesia regimens should be discussed with patients
- Patients on opiates should receive at least four hourly observations and pain scores should be documented
- Patients should be offered additional specialist nursing support and psychological support as needed
- Patients should be offered access to complementary and additional therapies through the Full Circle Fund as available
- On discharge there should be a
    - Plan for analgesia
    - Plan for follow up – nursing / medical / other
    - Discharge summary to primary care in a timely fashion

Patients admitted under other specialties should be

Elective Admission

- Elective admissions as day cases for regular transfusions, automated red cell exchanges, or planned interventions should be coordinated through the haematology scheduling team.
- Pre-admission assessments should include a review of medical history, transfusion protocols, and any psychological or pain management needs.

Outpatient Care

Outpatient care at SGUH comprises of providing annual reviews, treatment reviews (disease intervention, transfusion management, iron chelation, transplant management) psychology annual reviews, specialist nursing reviews and psychology reviews.

Clinic Schedule

Weekly haemoglobinopathy clinics – Wednesday afternoon

- annual reviews, 30 minute appointments

-Multidisciplinary input (CNS and psychology)

- new patient appointments

- face to face and telephone appointments available

Red Cell Treatment clinics – twice a month

Telephone appointment reviews, review of patients on hydroxycarbamide, iron chelation, and new therapies as they become available

Comprehensive Thalassaemia clinics – Wednesday afternoon 2-4 / year

Multidisciplinary annual and comprehensive review in dedicated thalassaemia clinic 2- 4 times/ year.

CNS clinics

CNS clinics are held weekly in parallel with medical and psychology clinics

Psychology clinics

In outpatient clinics, psychologists offer individual therapy sessions for patients living with red blood cell conditions, conduct annual reviews, and help connect patients to relevant external services, such as local talking therapies and mental health providers including options for external support during times of a mental health crisis when needed.

Patients who do not attend clinic

- If a patient fails to attend a scheduled appointment options include
    1. Attempt to contact the patient via CNS phone
    2. Send a follow-up letter or email offering a rescheduled appointment.
    3. In cases of repeated DNAs, discuss at local MDT – options for engagement may include CNS, community team or engagement with primary care.
- High-risk patients (e.g., frequent crisis admissions or transfusion-dependent patients) should be discussed more urgently at MDT

Follow up schedule for patients with SCD or Thalassaemia

- Patients with HbSS sickle cell – minimal complications
    - Annual face-face annual review clinic (Wednesday pm clinic)
    - 3 monthly telephone clinic review for HC / chelation review if appropriate (Red Cell Treatment Clinic)

- Patients with HbSS sickle cell with complex conditions
    - Annual face-face annual review clinic (Wednesday pm clinic)
    - 3 monthly telephone clinic review for HC / chelation review if appropriate (Red Cell Treatment Clinic)
    - Additional Wednesday pm clinic review as needed
- Patients with HbSC – minimal complications
    - Annual face-face annual review clinic (Wednesday pm clinic)
- Patients who are pregnant
    - 4 weekly minimum follow up in Wednesday pm clinic
- Patients with Transfusion Dependent Thalassaemia
    - Annual face-face annual review clinic (Thalassaemia clinic)
    - 3 monthly telephone clinic review for chelation review if appropriate (Red Cell Treatment Clinic)
    - Additional thalassaemia clinic review as needed
- Patients with Non-Transfusion Dependent Thalassaemia
    - Annual face-face annual review clinic (Thalassaemia clinic)
    - 3 monthly telephone clinic review for chelation review if appropriate (Red Cell Treatment Clinic)
    - Additional thalassaemia clinic review as needed
- Patients with alpha thalassaemia (HbH disease)
    - Annual face-face annual review clinic (Thalassaemia clinic)
    - 3 monthly telephone clinic review for chelation review if appropriate (Red Cell Treatment Clinic)
    - Additional thalassaemia clinic review as needed

Transfusion Services

SGUH provides routine and emergency transfusion services for patients with sickle cell, thalassaemia and rare inherited anaemias.

Top Up Transfusion

- Top up transfusions for patients with thalassaemia, rare anaemias and occasionally sickle cell disease occur on the Ruth Myles Day Unit.
- Patients will have an individual transfusion protocol with haemoglobin targets and transfusion risk assessments .
- Access difficulties will be monitored.

- Transfusion parameters and iron management will be monitored through clinic.
- Staff have appropriate transfusion, cannulation and haemoglobinopathy competencies

Apheresis Service

- Automated red blood cell exchange transfusion is provided in-house by trained practitioners
- Patients are referred for regular long term transfusion programmes after discussion at MDT with written consent taken before first procedure
- Patients have a referral prescription for target haematocrit, target S% and fraction of cells remaining
- Iron levels are monitored in clinic
- Decisions re elective one-off procedures are made in MDT (eg for surgical optimisation, delivery etc)
- There is an on call apheresis service for time sensitive emergencies that must be discussed and authorised by the haemoglobinopathy consultant or on call haematologist.
- Staff have appropriate transfusion, cannulation and haemoglobinopathy competencies

Apheresis and Transfusion Review Meetings

- Assess patient outcomes and adjust treatment protocols as needed.
- Involve both nursing and medical staff for comprehensive evaluation.

Multidisciplinary Team (MDT) Meeting Schedules

Weekly Team MDT Meetings (Wednesday pm)

- Attendees: Consultant haematologist, hospital CNS, community CNS, psychologist, pain management team when needed, patient coordinator, medical trainees and other relevant specialists.
- Purpose: Review and coordinate care plans, discuss complex cases, and address psychosocial aspects of care.
- Documentation: Meeting notes must be recorded and disseminated to all team members, with updates added to patient records.
- Deaths should be discussed
- Any complaints and serious concerns or incidents should be discussed

Monthly HCC MDTs

- For discussion of complex cases, deaths, or discussions of suitability and referral for novel or intensive therapy (eg stem cell transplant, gene editing treatment)

Emergency HCC MDT

- Can be assembled at short notice across the HCC via MS Teams to discuss critical time-sensitive complex cases where decisions need to be made urgently.

National Haemoglobinopathy MDT

- Monthly MDT for discussion of highly complex cases, deaths and consideration of intensive / curative therapies.

LHT MDT

- Each LHT should be invited to a routine twice yearly MDT where each patient on their books is discussed. This should cover
    - Attendance at SHT for annual review
    - Admissions at different hospitals
    - Access to individualised care plans
    - Suitability for novel or intensive therapy
    - Psychological or Social difficulties
    - Deaths, serious concerns, complaints

- Each LHT is also invited to the monthly HCC MDTs and can present patients there as needed or to the SGUH weekly MDT

Schedule

Trust	**SHT MDT timing**
St Helier's & Epsom	
Kingston	
Ashford St Peters (Chertsey)	March and September
Surrey & Sussex Healthcare (East Surrey)	January and July
Royal Surrey (Guildford)	March and September
Frimley Park	April and October

Specialty MDT

Medical MDTs are held with different subspecialties to support the care of patients with haemoglobinopathies. Schedule as below

Specialty	Schedule	Attendees
Orthopaedic	As needed	Orthopaedic consultant from complex arthroplasty service CNS orthopaedics Haemoglobinopathy consultant
Renal	Every 6 months June / December	Renal physician Haemoglobinopathy consultant
Obstetric	Monthly	Obstetric consultant Obstetric physician Specialist midwife Haemoglobinopathy consultant Haemoglobinopathy CNS
Obstetric birth plan MDT	One per patient at approx. 34/40	Obstetric consultant Obstetric Anaesthetic consultant Specialist midwife Haemoglobinopathy consultant Haemoglobinopathy CNS
Neurology (SW London Sickle Neuro MDT)	Every three months	Neurology consultant with interest in sickle cell Neurology consultant with stroke expertise Neuro-radiologist Haemoglobinopathy consultant
Endocrine / thalassaemia		
Cardiology / thalassaemia	Annual (February)	Cardiology consultant with expertise in cardiac iron loading Haemoglobinopathy consultant
Stem Cell Transplant MDT	Every three months	Stem Cell Transplant consultant Haemoglobinopathy consultant Transplant co-ordinator / fellow Haemoglobinopathy CNS
Transfusion MDT		Lead Transfusion Practitioner Haemoglobinopathy consultant

Coordination of Care with Other Services

Patients Moving to a New Area (e.g., University)

- Ensure continuity of care by liaising with the patient's new local haematology team.
- Provide a detailed transfer summary, including:
    - Diagnosis and treatment history
    - Current medications (e.g., hydroxycarbamide, chelation therapy)
    - Recent transfusion and iron overload data
    - Psychological and pain management needs
- Maintain contact with the receiving team for three months post-transfer to address any transition challenges.
- Ensure plan for treatment monitoring is in place

Shared Care Arrangements with Other Trusts

Principles of Shared Care

- Establish shared care agreements with referring trusts, defining responsibilities for consultation, treatment, and follow-up. (Service Level Agreement)
- Ensure patients have access to care closer to home without compromising quality.
- This should be in place for LHT services and community services.

Consultation and Review

- Patients under shared care with LHTs will have annual reviews in person at SGUH as the specialist service with multidisciplinary expertise available
- Plans for treatment monitoring should be agreed at the LHT MDT
- Inpatients can and should be discussed with SGUH for specialty opinion as required with consideration given to transfer of patient for specialist treatment as appropriate
- SGUH will ensure that LHTs have understanding of how to contact SGUH for advice both for emergency situations and routine queries.

Clear guidance and expectation should be in place about urgent referral pathways and indications for referral for inpatients and urgent outpatients to the SHT

Supporting Laboratory Services

- Ensure timely and accurate diagnostic support, including haemoglobin electrophoresis and iron studies.
- **UKAS accredited**
- provides antenatal services as well as diagnostic services
- HbS service available 24/7
- Staffing: Technical lead and two rotational staff
- Engages in UK NEQAS

Governance Arrangements

Clinical Governance

- The Red Cell Service Clinical Lead is responsible for ensuring adherence to guidelines and standards.
- The service will present regularly (at least annually) at departmental clinical governance meetings and discussions will include
    - Service delivery metrics
    - Adverse events or near misses
    - Patient and staff feedback
- Adverse events, near misses, complaints and feedback will also be discussed at weekly local MDT
- Action plans from governance meetings must be implemented and reviewed regularly.

Documentation and Reporting

- All consultations, assessments, and treatments must be documented in the patient's electronic health record contemporaneously.
- All members of the team must engage with Trust governance processes (eg PSIRF and datix) and attend clinical governance meetings.

Quality Assurance

- Regular audits of care pathways, transfusion practices, and MDT functioning will be conducted.
- Findings should be used to drive continuous improvement and compliance with NHS standards.

Key Performance Indicators (KPIs) – data monitored / regular audits

- Completion rates for annual reviews and MDT meetings.
- Percentage of patients with updated care plans.
- Engagement with HCC Audits

Feedback Mechanisms

Principles of co-production: Feedback from and to patients and carers is critical for identifying areas for improvement, ensuring services meet patient needs, and fostering trust in the care pathway

- Regular patient surveys to capture experiences and suggestions
  - Use of nationally mandated survey (picker, UKTS)
  - NHS Friends and Family feedback pathways

- Complaints will be responded to in line with Trust's complaints processes and discussed at local weekly MDT
- Focus Groups should be considered when considering specific changes or a need for information in service.
- Patients from SGUH are invited and attend the HCC monthly PPV (Patient and Public Voice) meetings where data and information is fed back.

Education

- All members of the team providing care for patients with sickle cell and thalassameia are expected to stay up to date with continuous professional development (CPD) appropriate to their role.

- CNS will be responsible for ensuring the availability and delivery of education for nursing colleagues who will be involved in the care of patients with sickle cell and thalassaemia – for example – ward nursing staff, day unit and apheresis nursing staff, ED nursing staff and midwives.

- Nursing competencies in line with RCN are established and to be completed

- Haemoglobinopathy consultants will be responsible for the delivery of education for doctors in training and locally employed doctors within the haematology department and for doctors in other areas that will be involved in both the emergency and elective care of patients with sickle cell and thalassaemia.

Review and Updates

- This policy will be reviewed every 3 years or sooner if significant changes to service occur.
- Amendments will be approved via Care Group Meetings and communicated to all staff.

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7. Dissemination

This document will be disseminated directly to key stakeholders and will be available on the haematology intranet page.

8. Consequences of Breaching the Policy

Failing to follow this policy could lead to action under the Trust's disciplinary policy.

9. Monitoring compliance

The table below outlines the process for monitoring compliance with this document.
Populate table.

Monitoring compliance and effectivenesstable					
Element/ Activity being monitored	**Lead/role**	**Methodology to be used for monitoring**	**Frequency of monitoring and Reporting arrangements**	**Acting on recommendations and Leads**	**Change in practice and lessons to be shared**
Engagement with standards of care for patients with sickle cell and thalassaemia	*Clinical lead for haemoglobinopathies*	*Engagement with national peer review programme*	*As required – usually every 3 years*	*Haematology*	*Via local MDT and clinical governance meetings*

10. Associated documentation

HAU Standard Operating Procedure
Red Blood Cell Exchange Standard Operating Procedure

11. References

No One's Listening - A Report » Sickle Cell Society

Standards for the Clinical Care of Adults with Sickle Cell in the UK - 2018

Advancing care quality and outcomes for haemoglobin disorders across England - NHS Midlands and Lancashire

Sickle cell and thalassaemia competency framework | Publications | Royal College of Nursing