SCHEDULE 2 – THE SERVICES

A. Service Specifications

1. Service name	Specialist Haemoglobinopathy Services (adults and children) • Specialist Haemoglobinopathy Teams
2. Service specification number	170126S
3. Date published	02/06/2025
4. Accountable Commissioner	NHS England *Blood and Infection Programme of Care* Email: *england.npoc-bloodandinfection@nhs.net*

5.	**Population and/or geography to be served**
5.1	**Population covered** Specialist Haemoglobinopathy Teams (SHTs) provide specialist care for adults and children with sickle cell disease (SCD), thalassaemia and rare inherited anaemias (RIAs) including those requiring transfusion and/or chelation therapy across their agreed geographical areas. Demographics vary across the country and as such population sizes will vary.
5.2	**Minimum population size** There are approximately 17,000 service users with SCD, 2,300 service users with thalassaemia (NHR, September 2023) and 1,000 service users with RIAs in England. A large number of service users are under 19 years of age. There were 227 babies born with SCD in England during 2020/21[1], compared with approximately 20-30 babies born each year with thalassaemia. This specification should be read in conjunction with service specification 170125S Haemoglobinopathy Coordinating Centres.
6.	**Service aims and outcomes**
6.1	**Service aims** The overall aim of the service is to reduce levels of morbidity and mortality and improve the outcomes and experience of all haemoglobinopathy service users by reducing inequalities and improving timely access to high quality expert care. The increasing life expectancy of individuals with these conditions means that the overall prevalence will rise, and services will need to develop to meet the changing needs and comorbidities developed throughout the service user's lifespan. Provision of high-quality services will contribute to reducing the overall health inequalities experienced by those with haemoglobinopathies due to high prevalence amongst

[1] Antenatal screening standards: data report 1 April 2020 to 31 March 2021 - GOV.UK (www.gov.uk)

groups with certain ethnic backgrounds who are more likely to be over-represented in deprived populations, and the social and economic impact of living with these conditions. Services will also need to adapt with the development of new treatments and technologies.

6.2 Outcomes

NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people from dying prematurely
Domain 2	Enhancing quality of life for people with long-term conditions
Domain 3	Helping people to recover from episodes of ill-health or following injury
Domain 4	Ensuring people have a positive experience of care
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm

Service defined outcomes/outputs

Reference	Domain	Rationale	Indicator
HAEM14	1	Service aims to reduce levels of morbidity and mortality of service users	Proportion of service users with sickle cell within the SHT geography who have had a serious adverse event in the reporting period
HAEM15	1	Service aims to reduce levels of morbidity and mortality of service users	Proportion of service users with thalassaemia or RIA within the SHT geography who have had a serious adverse event in the reporting period

The service will complete/upload data for all listed quality outcomes and metrics to the national Specialised Services Quality Dashboard (SSQD). The full definition of the quality outcomes and metrics and their descriptions including the numerators and denominators can be accessed at https://www.england.nhs.uk/commissioning/spec-services/npc-crg/spec-dashboards/.

The SHT should ensure that the Sickle Cell Society Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK, Sickle Cell Disease in Childhood Standards and Recommendations for Clinical Care and the UK Thalassaemia Society Standards for the Clinical Care of Children and Adults Living with Thalassaemia in the UK are being met.

The SHT must record complete, accurate and timely service user data on the National Haemoglobinopathy Registry (NHR). The SHT should also ensure that all service

	users in their network area are registered on the NHR. The SHT and newborn screening laboratory will be responsible for ensuring all children identified by the neonatal screening programme are incorporated into hospital care systems via the NHR.
7.	**Service description**
7.1	**Service model** The SHT will deliver care for a defined caseload of service users within a network in conjunction with Local Haemoglobinopathy Teams (LHTs). All Trusts treating service users with haemoglobinopathy are expected to be in network with an SHT to provide specialist care. It is the SHT's responsibility to develop and monitor pathways of care into the SHT for all service users in its network in close collaboration with their LHTs. The SHT will facilitate equitable access to specialised care for all service users within its geography, including those under the care of an LHT. Support will be in the form of 24/7 access to haematology advice either via on call arrangements from within the specialist staff team in the SHT or via arrangement with other regional and national specialists. As well as delivering specialised care, SHTs will provide routine care for their local service user population and ensure all other service users within their network receive annual reviews, either by clinicians from the SHT or by an arrangement with those at the LHT under supervision of the SHT. In the case of the latter, clear escalation pathways will be in place. Although most SHTs are responsible for whole-of-life care for service users with haemoglobinopathy and rare anaemias, some may be responsible for the care of children only, and others for adults only. In all cases, a robust pathway is necessary to ensure seamless transition from paediatric to adult services (be it in the same SHT or another SHT). See section 7.2 for further details. All providers are paid for activity in line with the NHS Payment Scheme. Additional funding is paid to HCCs and SHTs to provide their network responsibilities. The SHT will demonstrate close working with Integrated Care Boards and other providers to capitalise on the expertise available outside of the SHT when designing care pathways, including discharge planning.
7.2	**Pathways** <u>Overall patient pathway</u> Haemoglobinopathies and RIAs are lifelong conditions and service users will access both on-going routine, as well as specialist, care throughout their lifetime. Service users' care should be delivered as close to home as possible. Whilst rare and sometimes complex, the ongoing and routine monitoring and treatment of service users with haemoglobinopathy and RIA can be managed with the use of protocols, pathways and access to specialist expertise either at the SHT or HCC Multi-disciplinary Team (MDT).

The configuration of care provision will be based on networks linked to local prevalence, expertise and availability of service providers; this may include acute hospitals, community care, primary care and the voluntary sector.

The role of the SHT is to deliver specialist care and support the delivery of non-specialist aspects of care provided by other parts of the healthcare system. Routine outpatient, day case and inpatient care could be delivered by LHTs. However, SHTs undertake some elements of outpatient care such as annual reviews and the management of individuals with complex needs.

Specialist haemoglobinopathy services include all care provided by the SHT for which an expert multidisciplinary team is required and as outlined below.

<u>Specialised patient pathway</u>

Referral

New service users enter the service either as babies (including those notified through the NHS sickle cell and thalassaemia screening programme) or as new arrivals to England notified via GPs, community services, emergency departments and other clinical specialities. Service users may also move geographical area and register for local services or be diagnosed in adulthood. In all cases, the local care provider should notify the service user's SHT.

Care

SHTs are responsible for planning and overseeing the delivery of service user care. For some services this will be delivered directly by the SHT. For others, the SHT might make arrangements:

- with LHTs in the network, especially those that have a significant service user caseload and well developed services;
- with another SHT, where it cannot provide a particular aspect of care.

The SHT must establish formal agreements with local providers in accordance with national standards and guidelines.

As a minimum, all SHTs should provide:

- Specialist care for paediatric and adult service users, including referral for specialist diagnostic investigations, discussion of disease modifying treatments, discussion of new treatments and new trials, and neurocognitive assessment and review;
- Annual reviews that include agreed, up to date care plans, which are shared with LHTs as appropriate;
- Transition care from paediatric to adult services;
- Discussion on pregnancy planning;
- Transfusion management including decisions regarding initiation and cessation of elective transfusion programmes;

- Guidance on prescribing iron chelating drugs and monitoring iron overload and chelation toxicity;
- Specialist support and clinical advice;
- Initiation of hydroxycarbamide treatment, blood monitoring and dose escalation as appropriate;
- Advice on complex care surgery;
- Advice on acute organ failure or any other life threatening event;
- Key clinical information, including a comprehensive haemoglobinopathy history including alloantibody test results, within 2 weeks of receipt of request for patients choosing to transfer care or as part of shared care arrangements.

Providing clear pathways exist, an SHT may refer the following interventions to other SHTs within their network for:

- Neurocognitive assessment and review;
- MRI assessment of liver and cardiac iron;
- Management of complications related to iron overload and management of endocrine and growth;
- Management of complex service users and those with co-morbidities. This may entail working with other SHTs/their HCC to establish expert clinics, such as renal and cardiac;
- Advice and referral for stem cell transplant, novel and curative therapies;
- Specialist advice for the management of pregnancy in conjunction with expert obstetric teams.

Pregnancy

All women of childbearing age should receive personalised pre-pregnancy and maternity care from specialist services, in line with the shared management and escalation protocols agreed by the https://www.england.nhs.uk/publication/maternal-medicine-networks-service-specification/. Women with haemoglobinopathies must be referred immediately once they are pregnant to a high risk obstetric clinic. They must be reviewed early on within their first trimester by the SHT team or discussed in an appropriate MDT to monitor any disorder/disease specific aspects of pregnancy management; this must include access to termination of pregnancy and specialist advice regarding contraception. An individualised care plan must be in place that covers the antenatal, intrapartum and postnatal periods. It must include clear instructions for shared care with secondary services, including escalation and transfer protocols and clear guidelines for planned and emergency delivery.

Prevention and management of neurological complications of SCD through transcranial Doppler (TCD) scanning in childhood; specialised neuro-radiology, neurology and neuropsychology services

The SHT is responsible for:

- Providing up to date information relating to TCD screening, including acting on abnormal results and ensuring appropriate follow up;
- The coordination of access to TCD screening for all eligible children;

- The expert clinical management of those children and adults identified at risk of stroke and other neurological impairment to minimise the risk;
- The multidisciplinary team management of complex neurological abnormalities;
- Compliance with training and quality assurance schemes established to support continuous quality improvement.

Expert multidisciplinary care for complex service users

The SHT is responsible for the management of complex service users using an MDT approach. For children this will include growth, holistic development and academic achievement. Indicators of complexity include but are not limited to:

- Multi-system disease including organ damage;
- Mono system disease for example hepatic and renal disease;
- Abnormal neurology;
- Psychological and psychosocial problems;
- Pregnancy;
- Surgery;
- Orthopaedic issues;
- Endocrine complications;
- Cardiac complications especially related to iron overload;
- Infection prevention and control requirements.

The multidisciplinary team should include a medical lead, nursing representation (acute and community) and psychology. The MDT may require input from physiotherapy, neurology, cardiology, a radiographer and a sonographer.

There should be available and accessible processes in place to facilitate discussion of complex cases with the HCC. SHTs must follow the HCC process and ensure appropriate escalation.

Initiation, modification and cessation of long-term transfusion regimes and preventative therapy in SCD, Thalassaemia and RIA

- SHTs are responsible for the initiation, modification and cessation of long-term blood transfusion regimes.
- Regular administration and monitoring of top up transfusions should be carried out locally wherever possible and sessions should be designed to fit around the requirements of service users (e.g. evening clinics and out of hours transfusion).
- The SHT should ensure that access to automated red cell exchange transfusion for service users needing long term transfusion therapy is available.

Initiation, modification and cessation of long-term iron chelation, including monitoring complications of chelation

- The SHT must have access to annual endocrinopathy reviews for service users with thalassaemia and RIA aged 10 and above.

- The SHT must have access to cardiac and liver magnetic resonance scanning (this does not necessarily need to be on site).
- The initiation and amendment of long-term iron chelation regime is the responsibility of the SHT.
- The regular administration of iron chelation regime should be carried out locally wherever possible.
- The SHT should have access to neuro-psychological, psychosocial and social worker support for service users that struggle with concordance.

Acute management of severe and life threatening complications of SCD, Thalassaemia and RIA

The SHT must be able to clinically manage or have referral pathways in place for the following range of complications for SCD:

- Fulminant sepsis;
- Acute chest crisis;
- Acute splenic or hepatic sequestration;
- Ischaemic and haemorrhage stroke, including subarachnoid haemorrhage;
- Acute organ failure;
- Multi-organ failure;
- Priapism;
- Post-transfusion hyperhaemolysis and severe delayed haemolytic transfusion reactions;
- Ophthalmological complications (for example complications of sickle retinopathy/central retinal artery occlusion);
- Bone disease – osteomyelitis/osteonecrosis.

The SHT must be able to clinically manage or have agreed referral pathways in place for the following complications for thalassaemia and rare inherited anaemias:

- Heart failure and cardiac arrhythmias;
- Sepsis;
- Acute endocrine disturbances (for example hypocalcaemic tetany);
- Acute hepatic decompensation.

The SHT should offer formal liaison support to any acute provider within its network area, ensuring 24/7 access to appropriate clinical advice.

Long-term specific therapy for severe complicated SCD, Thalassaemia and RIA (complex long-term conditions management)

The SHT must be able to clinically manage (or have referral pathways in place within the network that have been agreed by the HCC) a range of progressive and often irreversible complications in both outpatient and inpatient settings.

Common to all SCD, Thalassaemia and RIA, these complications include:

- Pulmonary Hypertension and Cardiomyopathy;
- Chronic renal impairment;
- Leg ulceration;

- Chronic liver disease (cirrhosis portal hypertension, hepatic failure, hepatocellular carcinoma, often associated with transfusion-transmitted hepatitis B or C);
- Gallstones;
- Bone problems (avascular necrosis, osteoporotic fractures of the hips and spine, disc disease);
- Chronic pain;
- Thrombosis;
- Dental complications;
- Ophthalmological complications, such as retinopathy or drug related retinal damage.

In SCD, these complications include:

- Neurovascular disease, including Stroke;
- Chronic Respiratory Disease;
- Chronic renal impairment, including sickle nephropathy.

In transfusion dependent and non-transfusion dependent thalassaemia and RIA, these complications include:

- Endocrine dysfunction including growth hormone deficiency, hypogonadotrophic, hypogonadism, hypothyroidism, hypoparathyroidism, diabetes (which may require insulin treatment);
- Cardiac iron overload and related complications;
- Pseudoxanthoma;
- Exocrine Pancreatic Insufficiency.

The SHT must be able to initiate, modify and cease long-term medication regimes including, but not limited to, hydroxycarbamide, for instance to prevent or mitigate sickle painful episodes. The monitoring of such drug regimens is not a specialist function, but any modification based on the outcomes of that monitoring remains specialist.

The SHT should be able to provide access to psycho-social/psycho-neurological support to service users struggling to manage their condition.

Peri-operative management of sickle cell, thalassaemia and RIA service users requiring surgery

In principle all elective surgery, and where possible all emergency surgery, should be carried out at the SHT. In certain circumstances, a centre that is not an SHT may be best placed to undertake the surgical intervention and it will be for the SHT to agree appropriate surgical pathways. This should not delay life or organ preserving emergency surgery.

The SHT should demonstrate close liaison between haematologists, paediatricians, surgeons and anaesthetists. Surgeons and anaesthetists will have experience in the effective peri-operative management of SCD, thalassaemia and RIA service users with appropriate access to relevant clinical guidance.

The SHT is required to have pathways in place to manage emergency scenarios. Where a local acute provider is required to deliver emergency care, the local haematology team should liaise with the SHT.

Clinical governance and audit

The SHT will provide clinical leadership to the services provided within its geographical area. This will include:

- Reporting all adverse events to the NHR;
- Reporting adverse transfusion events to SABRE/SHOT;
- Undertaking an agreed number of clinical/quality audits as agreed with the HCC;
- Participating in the UKFHD peer review programme, ensuring that remedial action plans are agreed with commissioners;
- Ensuring compliance with network clinical guidelines and protocols;
- Submission of data to support local and national benchmarking.

Equitable service provision

The SHT will work with both the HCC and LHTs to develop an understanding of the service needs of the population served through:

- Regular assessment of characteristics within the SHT caseload, such as ethnicity, deprivation, cultural and linguistic differences;
- Use of health equity audit (HEAT) in partnership with the relevant LHTs to assess issues or differences regarding access to services;
- Gap analysis of healthcare needs and a plan to meet need, agreed with HCC network members.

Service user and carer engagement

The SHT will ensure service user/carer and public engagement through:

- Service user or user group input at meetings, such as HCC business meetings;
- Service user involvement in service planning and development;
- Engagement with local and national charities.

The SHT will promote user feedback and engagement with LHTs. Regular service user feedback, at least every 3 years using appropriate feedback tools, should be gathered.

Education and research

- The SHT must be able to provide access to appropriate and relevant local Trust training in sickle cell, thalassaemia and rare anaemia. This is for all relevant clinical staff including junior doctors, nurses and other allied health professionals involved in direct patient care;
- Training for nurses should meet a recognised competency framework for nursing haemoglobinopathy service users.

The responsibility for resourcing appropriate training for healthcare staff remains with the employing organisations.

The SHT must demonstrate a research portfolio, possibly linked to clinical and cost effectiveness of certain aspects of care.

Shared care arrangements

Individual formal agreements should be in place with each LHT, depending on the capacity of each LHT to deliver aspects of the service, covering:

- Delegation of annual reviews to the LHT;
- New service user and annual review guidelines;
- LHT management and referral guidelines;
- NHR data collection;
- Two-way communication of service user information between the SHT and LHT;
- Access to MDT meetings;
- Participation in network audits;
- Joint clinics, where needed.

Some LHTs may, with the agreement of the SHT, also provide some aspects of specialist care within the network (e.g. if there is specific surgical expertise within the Trust). This will be agreed on a Trust by Trust basis.

A standard operating procedure should be agreed between the SHT and LHT(s) that clearly specifies indications for immediate transfer, early referral, routine referral and cases to refer for discussion in the HCC/SHT MDT.

Transition

All healthcare services are required to deliver developmentally appropriate healthcare to service users and families. Children and young people with ongoing healthcare needs may present direct to adult services or may be required to transition into adult services from children's services.

Transition is defined as a 'purposeful and planned process of supporting young people to move from children's to adults' services'. Poor planning of transition and transfer can result in a loss in continuity of treatment, service users being lost to follow up, service user disengagement, poor self-management and inequitable health outcomes for young people. It is therefore crucial that adult and children's NHS services, in line with what they are responsible for, plan, organise and implement transition support and care (for example, holding joint annual review meetings with the child/young person, their family/carers, the children's and adult service). This should ensure that young people are equal partners in planning and decision making and that their preferences and wishes are central throughout transition and transfer. NICE guidelines recommend that planning for transition into adult services should start by age 13-14

	years at the latest, or as developmentally appropriate and continue until the young person is embedded in adult services.
7.3	**Clinical networks** The SHT is required to actively participate in the HCC network to enable services to be delivered as part of a co-ordinated, combined whole system approach. SHTs will act as the lynchpin of a local network of haemoglobinopathy services, supporting and encouraging LHTs to take an active part in the HCC network to improve care pathway coordination and improve outcomes for service users. SHTs may wish to refer particularly complex cases or cases where learning has occurred via the HCC for discussion at the National Haemoglobinopathy Panel MDT.
7.4	**Essential staff groups** • Medical Leadership: the SHT must have a named medical lead at consultant level. This must be a haematologist/paediatric haematologist or a paediatrician with expertise in haemoglobinopathies. Dependent on the configuration of acute care, there may be two medical leads to cover paediatric and adult care. • The SHT must have a named medical deputy lead at consultant level responsible for haemoglobinopathy care. There may be two deputies i.e. one each for paediatric and adult care. • Nursing leadership: the SHT must identify a lead nurse and should have a named deputy. There may be two deputies i.e. one each for paediatric and adult care. The lead nurse will support all nurses across the SHT and LHTs with education and specialist training. Education should cover all aspects of haemoglobinopathy specialist care, including sickle cell disease, thalassaemia and rare anaemias (with separate lead nurses for each where possible). • Community Nursing: the SHT must work in partnership with community health care teams with specialist nurses whose duties will include supporting service users with haemoglobinopathies and families with newborns with haemoglobinopathy diagnoses. • Pharmacist: the SHT should have a named (lead) pharmacist for service users with haemoglobinopathies whose role will include drafting protocols for local delivery of drug therapies, involvement in outpatient clinics and ensuring appropriate medication management for sickle cell drugs. The SHT must have access to the following services/clinical specialists experienced in treating service users with haemoglobinopathies: • Psychologist with a specialist interest in haemoglobinopathies; • Inpatient and outpatient physiotherapy; • Occupational Therapy; • Dietetics; • Benefits/social worker support; • Acute and chronic pain team; • Consultant cardiologist; • Consultant respiratory physician;

	• Consultant teams with experience in managing pulmonary hypertension; • Consultant nephrologist and access to renal replacement therapy and transplant; • Consultant hepatologist; • Consultant urologist with expertise in managing priapism, erectile dysfunction; • Consultant neurologist and acute stroke service; • Consultant ophthalmologist; • Consultant endocrinologist; • Consultant gastroenterologist; • Contraception and sexual health services; • Genetic counselling and fertility services; • Consultant obstetrician; • Consultant general surgeon; • Tissue viability service/leg ulcer clinic; • Maxillo-facial surgeons or tertiary dentists; • Play therapy for paediatrics.
7.5	**Essential equipment and/or facilities** <u>Laboratory services</u> United Kingdom Accreditation Service (UKAS) / Clinical Pathology Accreditation (CPA) accredited laboratory services with satisfactory performance in the National External Quality Assessment Service (NEQAS) haemoglobinopathy scheme and Medicine and Healthcare Products Regulatory Agency (MHRA) compliance for transfusion should be available at all times (other than genetics services which can be provided in working hours only). The SHT must be able to access the range of laboratory tests and transfusion support to manage elective and emergency service users. <u>Critical care</u> • The SHT must have an adult Intensive Care Unit (ICU) on site unless it is a paediatric unit. • If the SHT does not have a Paediatric Intensive Care (PICU) on site, they must demonstrate formal arrangements with either other SHTs or other acute Trusts with a PICU. <u>Access to Bone Marrow and Stem Cell Transplantation</u> Both interventions are deemed supra-specialised and will be available at only a few centres nationally. The SHT must have formal processes in place to consider service users for such clinical interventions and to refer to the HCC MDT for discussion.

7.6 Interdependent Service Components – Links with other NHS services

Interdependent Service	Relevant Service Specification/Standards	Proximity to service
Haemoglobinopathy Coordinating Care Centres	NHS England » Specialist Haemoglobinopathy Services	Within network geography

7.7 Additional requirements

None

7.8 Commissioned providers

The list of commissioned providers for the services covered by this specification is available at https://www.england.nhs.uk/commissioning/spec-services/npc-crg/blood-and-infection-group-f/haemoglobinopathies/specialised-haemoglobinopathy-services/

7.9 Links to other key documents

Please refer to the *https://www.england.nhs.uk/publication/manual-for-prescribed-specialised-services/* for information on how the services covered by this specification are commissioned and contracted for.

Please refer to the https://www.england.nhs.uk/commissioning/spec-services/key-docs/#id-rules tool for information on how the activity associated with the service is identified and paid for.

Please refer to the relevant Clinical Reference Group webpages for NHS England Commissioning Policies which define access to a service for a particular group of service users. The specific clinical policies that relate to the services covered by this service specification include:

- https://www.england.nhs.uk/publication/clinical-commissioning-policy-allogeneic-haematopoietic-stem-cell-transplantation/
- https://www.england.nhs.uk/publication/allogeneic-haematopoietic-stem-cell-transplantation-for-adults-with-sickle-cell-disease/
- https://www.england.nhs.uk/publication/rituximab-and-eculizumab-for-the-prevention-and-management-of-delayed-haemolytic-transfusion-reactions-and-hyperhaemolysis-in-patients-with-haemoglobinopathies/
- https://www.england.nhs.uk/publication/clinical-commissioning-policy-treatment-of-iron-overload-for-transfused-and-non-transfused-patients/
- https://www.england.nhs.uk/wp-content/uploads/2018/07/Pre-implantation-genetic-diagnosis.pdf

Relevant NICE guidelines:

- Medical Technologies Guidance MTG28: Spectra Optia for automatic red blood cell exchange in people with sickle cell disease https://www.nice.org.uk/guidance/mtg28
- Clinical guideline CG143 Sickle cell disease: managing acute painful episodes in hospital https://www.nice.org.uk/guidance/cg143

Relevant clinical guidelines from the British Society of Haematology:

- https://b-s-h.org.uk/guidelines/guidelines/gl-management-of-sickle-cell-disease-in-pregnancy
- https://b-s-h.org.uk/guidelines/guidelines/red-blood-cell-specifications-for-patients-with-hemoglobinopathies-a-systematic-review-and-guideline-ictm-collaboration
- https://b-s-h.org.uk/guidelines/guidelines/guidelines-for-the-use-of-hydroxycarbamide-in-children-and-adults-with-sickle-cell-disease
- https://b-s-h.org.uk/guidelines/guidelines/red-cell-transfusion-in-sickle-cell-disease-part-I
- https://b-s-h.org.uk/guidelines/guidelines/red-cell-transfusion-in-sickle-cell-disease-part-ii
- https://b-s-h.org.uk/guidelines/guidelines/management-of-acute-chest-syndrome-in-sickle-cell-disease
- Significant haemoglobinopathies: A guideline for screening and diagnosis https://onlinelibrary.wiley.com/doi/full/10.1111/bjh.18794
- https://b-s-h.org.uk/guidelines/guidelines/guidelines-for-the-monitoring-and-management-of-iron-overload-in-patients-with-haemoglobinopathies-and-rare-anaemias
- https://b-s-h.org.uk/guidelines/guidelines/the-use-of-next-generation-sequencing-in-the-diagnosis-of-rare-inherited-anaemias-a-joint-bsheha-good-practice-paper

UK Thalassaemia Society Standards:

- https://ukts.org/wp-content/uploads/2021/02/Standards-for-the-Clinical-Care-of-Children-and-Adults-Living-with-Thalassaemia-in-the-UK-4th-Edition-2023.pdf

Sickle Cell Society Standards:

- https://www.sicklecellsociety.org/wp-content/uploads/2018/05/Standards-for-the-Clinical-Care-of-Adults-with-Sickle-Cell-in-the-UK-2018.pdf
- https://www.sicklecellsociety.org/wp-content/uploads/2019/11/SCD-in-Childhood_Final-version-1.pdf

UKFHD Quality Standards for Health Services for People with Haemoglobin Disorders:

- https://haemoglobin.org.uk/3d-flip-book/qs-haemoglobin-disorders-v5-2-pdf/

Date Published: June 2025

Change form for published Specifications and Products developed by Clinical Reference Group (CRGs)

Product name: Specialist Haemoglobinopathy Services (adults and children) - Specialist Haemoglobinopathy Teams

Publication number: 170126S

CRG Lead: Blood & Infection Clinical Lead

Description of changes required

Describe what was stated in original document	Describe new text in the document	Section/Paragraph to which changes apply	Describe why document change required	Changes made by	Date change made
Format change: the content of the original service specification has been transferred into the updated NHS England Specialised Service Specification Template. As a result, some sections have been removed in line with guidance to make service specifications shorter, more precise and therefore more accessible.	Formatting changes throughout the document	Throughout	A new service specification template was published in 2022	SWG	Jan 2024-Feb 2025
The overall aim of the service is to reduce levels of morbidity and mortality and improve the experience of all haemoglobinopathy patients by reducing inequities and improving timely access to high quality expert care.	The overall aim of the service is to reduce levels of morbidity and mortality and improve the outcomes and experience of all haemoglobinopathy service users by reducing inequalities and improving timely access to high quality expert care.	1.2 Aim of the service / 6.1 Service aims	Amended to reflect feedback from clinicians and service users on key aims and request from POC Assurance Group to highlight	SWG	Jan 2024-Mar 2025

Date Published: June 2025

Specialist haemoglobinopathy services include all care provided by specialist haemoglobinopathy teams including inpatient care where the cause of admission is related to haemoglobinopathy and outreach when delivered as part of a provider network. This applies to provision in adults and children. The purpose of this specification is to outline the responsibilities of Specialist Haemoglobinopathy Teams (SHTs) and the relationships that need to be in place with the local Haemoglobinopathy Coordinating Centre (HCC), the wider health economy and patients. 3.2 Understanding Local Population Needs The increasing life expectancy of individuals with these conditions means that the overall prevalence will increase and services will	The increasing life expectancy of individuals with these conditions means that the overall prevalence will rise, and services will need to develop to meet the changing needs and comorbidities developed throughout the service user's lifespan. Provision of high-quality services will contribute to reducing the overall health inequalities experienced by those with haemoglobinopathies due to high prevalence amongst groups with certain ethnic backgrounds who are more likely to be over-represented in deprived populations, and the social and economic impact of living with these conditions. Services will also need to adapt with the development of new treatments and technologies.		deprived population.		

need to develop to meet the needs of older patients with the additional comorbidities encountered with age. Over time, the advent of new treatments such as gene therapy has the potential to change the prevalence of haemoglobinopathy disorders. Services will need to develop to meet the needs of their local populations. This may mean using outreach and technology to share expertise.					
This specification applies to: all children and adults with Sickle Cell Disease and Thalassaemia. It also applies to children and adults with other inherited anaemias if they require intermittent or long term transfusion and/or chelation therapy. This includes Blackfan Diamond anaemia, pyruvate kinase deficiency and congenital sideroblastic anaemia amongst other rare disorders.	Specialist Haemoglobinopathy Teams (SHTs) provide specialist care for adults and children with sickle cell disease (SCD), thalassaemia and rare inherited anaemias (RIAs) including those requiring transfusion and/or chelation therapy across their agreed geographical areas. Demographics vary across the country and as such population sizes will vary.	1.2 Aim of the service / 5.1 Population Covered	More concise	SWG	Jan 2024-Feb 2025

The SHTs will deliver care with local Haemoglobinopathy Teams LHTs and other local hospitals and care providers for a defined caseload of patients within a network of care. All English Trusts treating patients with a haemoglobinopathy are expected to be part of a network.	The SHT will deliver care for a defined caseload of service users within a network in conjunction with Local Haemoglobinopathy Teams (LHTs). All Trusts treating service users with haemoglobinopathy are expected to be in network with an SHT to provide specialist care. It is the SHT's responsibility to develop and monitor pathways of care into the SHT for all service users in its network in close collaboration with their LHTs.	1.3 Specialist Haemoglobinopathy Teams / 7.1 Service model	Additional clarity	SWG	Jan 2024-Feb 2025
The diagram below describes the network and relationship between the teams.	Diagram removed	1.3 Specialist Haemoglobinopathy Teams	SWG considered diagram to depict an incorrect hierarchical relationship between network providers	SWG	Jan 2024-Feb 2025
The Specialist Haemoglobinopathy Team (SHT) will work with a specific Haemoglobinopathy Coordinating Centre (HCC) to ensure that the roles and responsibilities for its caseload of patients are clear.	The SHT will facilitate equitable access to specialised care for all service users within its geography, including those under the care of an LHT. Support will be in the form of 24/7 access to haematology advice either via	1.3 Specialist Haemoglobinopathy Teams / 7.1 Service model	Amended to make more succinct and provide additional clarity on role of SHTs and LHTs	SWG	Jan 2024-Feb 2025

The SHT will agree and monitor compliance with network care pathways and treatment protocols (elective and emergency) for its caseload of patients. The SHT will also support the provision of coordinated expert care and advice within the network. The SHT will provide 24/7 advice for other clinical teams both within the hospital and with other local hospitals. This does not mean 24/7 access to specialists, but there must be a minimum standard of 24/7 cover. This may be either directly or as part of a shared-care arrangement with other SHTs, as the aim is to provide equitable access to specialised care. It will be up to the SHT to decide how best to incorporate and develop on-line and existing sources of advice. NHS Blood and	on call arrangements from within the specialist staff team in the SHT or via arrangement with other regional and national specialists. As well as delivering specialised care, SHTs will provide routine care for their local service user population and ensure all other service users within their network receive annual reviews, either by clinicians from the SHT or by an arrangement with those at the LHT under supervision of the SHT. In the case of the latter, clear escalation pathways will be in place. Although most SHTs are responsible for whole-of-life care for service users with haemoglobinopathy and rare anaemias, some may be responsible for the care of children only, and others for adults only. In all cases, a robust pathway is necessary to ensure seamless transition from paediatric to adult services (be it in the same				

Transplant (NHSBT) may provide information on transfusions, although not advice on whether to transfuse or not. The NHR is being developed, which may enable it to be used as a resource. The SHT will support the provision of routine, non-complex care for its local population and will be responsible for ensuring that they all have an annual review. This may be in LHTs and local hospitals, depending on the needs of the individual patient. However, wherever the care is provided, it will follow a consistent approach through network, regional and national collaboration.	SHT or another SHT). See section 7.2 for further details.				
The SHT, with support from its HCC, will oversee and support the production of a training and development plan for all healthcare staff involved in the delivery of haemoglobinopathy care in its network area.	None	1.3 Specialist Haemoglobinopathy Teams	Removed based on stakeholder feedback – this is an HCC function	SWG	Jan 2024-Feb 2025

The SHT will ensure all consented patients in their network area are registered on the National Haemoglobinopathy Registry (NHR).	The SHT should ensure that all service users in their network area are registered on the NHR.	1.3 Specialist Haemoglobinopathy Teams / 7.1 Service Model	The NHR is now a non-consented registry	SWG	Jan 2024-Feb 2025
1.4 National Haemoglobinopathy Panel	None	1.4 National Haemoglobinopathy Panel	There is a separate ToR for the NHP	SWG	Jan 2024-Feb 2025
1.5 National Haemoglobinopathy Registry	None	1.5 National Haemoglobinopathy Registry	There is a separate ToR for the NHR	SWG	Jan 2024-Feb 2025
Specialist Haemoglobinopathy Services …does not include routine inpatient, day case and outpatient care, which is funded through existing tariff arrangements. Routine outpatient care is not funded through specialised commissioning. However, some local pricing arrangements mean SHTs are funded to undertake some elements of outpatient care, such as annual reviews and the management of individuals with complex needs. Further work on this	All providers are paid for activity in line with the NHS Payment Scheme. Additional funding is paid to HCCs and SHTs to provide their network responsibilities.	1.6 How the Service is Differentiated from Services Falling within the Responsibilities of Other Commissioners / 7.1 Service model	Updated to reflect current funding arrangements	SWG	Jan 2024-Feb 2025

will be progressed as part of future tariff arrangements.					
Whilst rare and sometimes complex, the ongoing and routine monitoring and treatment of patients with haemoglobinopathy and RIA can be managed with the use of protocols, pathways and access to specialist expertise either at the SHT or HCC/ national panel level.	Whilst rare and sometimes complex, the ongoing and routine monitoring and treatment of service users with haemoglobinopathy and RIA can be managed with the use of protocols, pathways and access to specialist expertise either at the SHT or HCC Multi-disciplinary Team (MDT).	2.1 Care Pathway / 7.2 Pathways	Additional clarity regarding specialist expertise	SWG	Jan 2024-Feb 2025
Pathways for paediatric and adult thalassaemia, sickle cell and RIAs feature both routine and specialised care. The role of the SHTs is to deliver and support the delivery of both specialised and non-specialised aspects of care.	The role of the SHT is to deliver specialist care and support the delivery of non-specialist aspects of care provided by other parts of the healthcare system. Routine outpatient, day case and inpatient care could be delivered by LHTs. However, SHTs undertake some elements of outpatient care such as annual reviews and the management of individuals with complex needs.	2.1 Care Pathway / 7.2 Pathways	Additional clarity on role of SHTs and LHTs	SWG	Jan 2024-Feb 2025
In all cases, the care provider should be notified in accordance with the	In all cases, the local care provider should notify the service user's SHT.	2.2 Referral / 7.2 Pathways	Distinction between HCC and SHT	SWG	Jan 2024-Feb 2025

specification for care and should in turn notify the HCC.					
The SHT might make arrangements: • with LHTs in the network especially those which have a significant patient caseload and well developed services • with another SHT, where it cannot provide a particular aspect of care. For both, this will be through a sub-contracting arrangement and such providers will be reimbursed to assist in the delivery of these functions. It is the responsibility of SHTs to establish local agreements with providers in accordance with national standards and guidelines.	The SHT might make arrangements: • with LHTs in the network, especially those that have a significant service user caseload and well developed services; • with another SHT, where it cannot provide a particular aspect of care. The SHT must establish formal agreements with local providers in accordance with national standards and guidelines.	2.3 Care / 7.2 Pathways	Removed specific reference to sub-contracting arrangement to future-proof for changes to national standards / guidelines	SWG	Jan 2024-Feb 2025
As a minimum, all SHTs should provide… • Prescription and routine monitoring of iron chelating drugs	As a minimum, all SHTs should provide… • Guidance on prescribing iron chelating drugs and monitoring iron overload and chelation toxicity;	2.3 Care / 7.2 Pathways	Amended to reflect that LHTs will prescribe and routinely monitor iron chelating drugs with guidance from SHT	SWG	Jan 2024-Feb 2025

As a minimum, all SHTs should provide…	Addition of: • Key clinical information, including a comprehensive haemoglobinopathy history including alloantibody test results, within 2 weeks of receipt of request for patients choosing to transfer care or as part of shared care arrangements.	2.3 Care / 7.2 Pathways	To highlight continuity of care when people change care provider	SWG	April 2025
All women of child bearing age should receive personalised pre-pregnancy and maternity care planning from specialised services.	All women of childbearing age should receive personalised pre-pregnancy and maternity care from specialist services, in line with the shared management and escalation protocols agreed by the local Maternal Medicine Network.	2.4 Pregnancy / 7.2 Pathways	To highlight that the provision of all medical management in pregnancy should be in line with the local MMN's shared protocols	Maternity and Neonatal Programme	May 2024
Within the defined network area, interdependencies with other services include: • HCCs, other SHTs, LHTs and local care services • National Haemoglobinopathy Panel • Acute providers • Primary care • Community healthcare services	Link provided to HCC service specification	2.5 Interdependence with other Services / 7.6 Interdependent Service Components – Links with other NHS services	New template	SWG	Jan 2024-Feb 2025

Date Published: June 2025

• Antenatal and new-born regional screening programmes • Genetic counsellors and specialists • Local authority and public health • Education providers • Social care • Voluntary sector • Sickle Cell and Thalassaemia Screening Programme					
This specification will apply to: all children and adults with Sickle Cell Disease and Thalassaemia and other inherited anaemias requiring transfusion and chelation therapy such as Blackfan Diamond anaemia, pyruvate kinase deficiency and congenital sideroblastic anaemia amongst other rare disorders. The service outlined in this specification is for patients ordinarily resident in England*; or otherwise the	Specialist Haemoglobinopathy Teams (SHTs) provide specialist care for adults and children with sickle cell disease (SCD), thalassaemia and rare inherited anaemias (RIAs) including those requiring transfusion and/or chelation therapy across their agreed geographical areas. Demographics vary across the country and as such population sizes will vary.	3.1 Population covered by this specification / 5.1 Population Covered	New template guidance and more concise as duplicated in 1.2	SWG	Jan 2024-Feb 2025

commissioning responsibility of the NHS in England (as defined in Who Pays?. Establishing the responsible commissioner and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges). Note: for the purposes of commissioning health services, this excludes patients who, whilst resident in England, are registered with a GP Practice in Wales, but includes patients resident in Wales who are registered with a GP Practice in England.					
There are about 1,500 patients with thalassaemia and 15,000 with SCD in England and circa 1,000 patients with rare inherited anaemias. A large number are under 19 years of age. Around 250 babies are born in England each year with SCD, compared with 20-30 babies with thalassaemia.	There are approximately 17,000 service users with SCD, 2,300 service users with thalassaemia (NHR, September 2023) and 1,000 service users with RIAs in England. A large number of service users are under 19 years of age. There were 227 babies born with SCD in England during 2020/21, compared with approximately	3.2 Understanding Local Population Needs / 5.2 Minimum population size	New template and updated data	SWG	Jan 2024-Feb 2025

Nearly all SCD affected children born in England, and the majority with thalassaemia, will be identified by the NHS Sickle Cell and Thalassaemia Screening programme. Other new patients may present through immigration or late diagnosis. The patient population is unevenly distributed through the country, making equity of access a priority. Life expectancy for both conditions is progressively improving and is now likely to be in excess of 50 years. Maximising quality of life is an important factor in the organisation of care and in treatment decisions. Patients with rare inherited anaemias are scattered throughout England and are often diagnosed late and managed by local haematologists and paediatricians. The numbers of patients in this population	20-30 babies born each year with thalassaemia.				

are unknown but expected to be relatively small.					
Evidence Base	Links to other key documents	4.1 Evidence Base / 7.9 Links to other key documents	New template and updated evidence	SWG	Jan 2024-Feb 2025
Evidence Base The standards, guidelines and quality requirements referred to include…	The Provider should ensure that the Sickle Cell Society Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK, Sickle Cell Disease in Childhood Standards and Recommendations for Clinical Care and the UK Thalassaemia Society Standards for the Clinical Care of Children and Adults Living with Thalassaemia in the UK are being met.	4.1 Evidence Base / 6.2 Outcomes	More explicit that standards should be met	SWG	Jan 2024-Feb 2025

Quality Indicators	Outcomes	4.2 Quality Indicators / 6.2 Outcomes	New template	SWG	Jan 2024-Feb 2025
Clinical Leadership Describes medical leadership and: Nursing leadership – the SHT will identify a lead nurse. There may be two deputies i.e. one each for paediatric and adult care. The lead nurse will support all nurses across the SHT and linked hospitals.	Essential staff groups Describes medical leadership and: • Nursing leadership: the SHT must identify a lead nurse and should have a named deputy. There may be two deputies i.e. one each for paediatric and adult care. The lead nurse will support all nurses across the SHT and LHTs with education and specialist training. Education should cover all aspects of haemoglobinopathy specialist care, including sickle cell disease, thalassaemia and rare anaemias (with separate lead nurses for each where possible). • Community Nursing: the SHT must work in partnership with	5.3 Other Applicable Local Standards / 7.4 Essential staff groups	Highlight importance of education, working with community nursing teams and input from pharmacy	SWG	Jan 2024-Feb 2025

	community health care teams with specialist nurses whose duties will include supporting service users with haemoglobinopathies and families with newborns with haemoglobinopathy diagnoses. • Pharmacist: the SHT should have a named (lead) pharmacist for service users with haemoglobinopathies whose role will include drafting protocols for local delivery of drug therapies, involvement in outpatient clinics and ensuring appropriate medication management for sickle cell drugs.				
The SHT must be able to demonstrate responsibility for: • The coordination of access to TCD screening for all eligible children. • The expert clinical management of those children and adults identified at risk of stroke	The SHT is responsible for: • Providing up to date information relating to TCD screening, including acting on abnormal results and ensuring appropriate follow up;	5.3 Other Applicable Local Standards / 7.2 Pathways	Additional clarity	SWG	Jan 2024-Feb 2025

and other neurological impairment to minimise the risk. • The multidisciplinary team management of complex neurological abnormalities. • Compliance with training and quality assurance schemes established to support continuous quality improvement.	• The coordination of access to TCD screening for all eligible children; • The expert clinical management of those children and adults identified at risk of stroke and other neurological impairment to minimise the risk; • The multidisciplinary team management of complex neurological abnormalities; • Compliance with training and quality assurance schemes established to support continuous quality improvement.				
The multidisciplinary team should include the following professionals: • Medical lead, nursing representation (acute and community) and psychology. • The multidisciplinary team may require input from physiotherapy, neurology, cardiology, radiographer and sonographer.	The multidisciplinary team should include a medical lead, nursing representation (acute and community) and psychology. The MDT may require input from physiotherapy, neurology, cardiology, a radiographer and a sonographer. There should be available and accessible processes in place to facilitate discussion of	5.3 Other Applicable Local Standards / 7.2 Pathways	Reduce duplication and highlight escalation process	SWG	Jan 2024-Feb 2025

• All patients to be reviewed at least annually by the SHT or under the supervision of the SHT. • Multidisciplinary team teams will review and oversee the overall progress of all patients with clinical complexities to optimise overall care.	complex cases with the HCC. SHTs must follow the HCC process and ensure appropriate escalation.				
Initiation, Modification and Cessation of Long-Term Transfusion Regimes and Preventative Therapy in SCD&T	Initiation, modification and cessation of long-term transfusion regimes and preventative therapy in SCD, Thalassaemia and RIA	5.3 Other Applicable Local Standards / 7.2 Pathways	Addition of RIA	SWG	Jan 2024-Feb 2025
Initiation, Modification and Cessation of Long-Term Iron Chelation. Monitoring of Complications of Chelation	Initiation, modification and cessation of long-term iron chelation, including monitoring complications of chelation Addition of: • The SHT must have access to annual endocrinopathy reviews for service users with thalassaemia and RIA aged 10 and above.	5.3 Other Applicable Local Standards / 7.2 Pathways	Specify importance of annual endocrinopathy reviews	SWG	Jan 2024-Feb 2025

Acute Management of Severe and Life Threatening Complications of SCD and Thalassemia The SHT will develop guidelines to implement the NICE guidance on the management of acute painful episodes. The SHT will be able to clinically manage or have referral pathways for the following range of complications for SCD: • Fulminant sepsis. • Acute sickle lung syndrome. • Acute splenic or hepatic sequestration. • Ischaemic and haemorrhage stroke. • Subarachnoid haemorrhage. • Acute renal failure. • Multi-organ failure. • Billiary obstruction. • Priapism. • Post-transfusion hyperhaemolysis and	Acute management of severe and life threatening complications of SCD, Thalassaemia and RIA The SHT must be able to clinically manage or have referral pathways in place for the following range of complications for SCD: • Fulminant sepsis; • Acute chest crisis; • Acute splenic or hepatic sequestration; • Ischaemic and haemorrhage stroke, including subarachnoid haemorrhage; • Acute organ failure; • Multi-organ failure; • Priapism; • Post-transfusion hyperhaemolysis and severe delayed haemolytic transfusion reactions; • Ophthalmological complications (for example complications of sickle retinopathy/central retinal artery occlusion);	5.3 Other Applicable Local Standards / 7.2 Pathways	Addition of RIA, removed reference to NICE guidance as included in 7.9, updated terminology and highlighted importance of 24/7 access to clinical advice	SWG	Jan 2024-Feb 2025

severe delayed haemolytic transfusion reactions • Acute ophthalmological complications (for example complications of sickle retinopathy/central retinal artery occlusion). • Osteonecrosis of major joints (for example hip, shoulder). The SHT will be able to manage or have agreed referral pathways the following complications for thalassaemia and rare inherited anaemias: • Heart failure and cardiac arrhythmias. • Infection prevention and control. • Post-splenectomy sepsis. • Acute endocrine disturbances (for example hypocalcaemic tetany). • Acute hepatic decompensation. The SHT will offer formal liaison support to any acute	• Bone disease – osteomyelitis / osteonecrosis. The SHT must be able to clinically manage or have agreed referral pathways in place for the following complications for thalassaemia and rare inherited anaemias: • Heart failure and cardiac arrhythmias; • Sepsis; • Acute endocrine disturbances (for example hypocalcaemic tetany); • Acute hepatic decompensation. The SHT should offer formal liaison support to any acute provider within its network area, ensuring 24/7 access to appropriate clinical advice.				

provider within its network area.					
Long-Term Specific Therapy for Severe Complicated SCD and Thalassaemia (Complex Long-Term Conditions Management)	Long-term specific therapy for severe complicated SCD, Thalassaemia and RIA (complex long-term conditions management)	5.3 Other Applicable Local Standards / 7.2 Pathways	Addition of RIA and list of complications updated	SWG	Jan 2024-Feb 2025
The SHT must be able to provide psycho-social/psycho-neurological support to complex patients struggling to manage their condition.	The SHT should be able to provide access to psycho-social/psycho-neurological support to service users struggling to manage their condition.	5.3 Other Applicable Local Standards / 7.2 Pathways	Stakeholder feedback that all service users would need to be assessed to identify complex ones – removed and changed to "should"	SWG	Jan 2024-Feb 2025
Peri-Operative Management of Sickle Cell and Thalassaemia Patients Requiring Surgery In principle all elective surgery, and where possible all emergency surgery, should be carried out in at the SHT. For practical purposes this may not be possible or desirable and it will be for the Local Area	Peri-operative management of sickle cell, thalassaemia and RIA service users requiring surgery In principle all elective surgery, and where possible all emergency surgery, should be carried out at the SHT. In certain circumstances, a centre that is not an SHT may be best placed to undertake the surgical intervention and it	5.3 Other Applicable Local Standards / 7.2 Pathways	Addition of RIA and additional clarity	SWG	Jan 2024-Feb 2025

Team and the SHT to agree surgical pathways.	will be for the SHT to agree appropriate surgical pathways. This should not delay life or organ preserving emergency surgery.				
Management of Pregnant Women with SCD and Thalassaemia	Pregnancy already covered in section 7.2	5.3 Other Applicable Local Standards	Duplication	SWG	Jan 2024-Feb 2025
Clinical Governance and Audit The SHT will adopt a clinical governance and leadership function. This will include… • Participating in any peer review process	Clinical governance and audit The SHT will provide clinical leadership to the services provided within its geographical area. This will include… • Participating in the UKFHD peer review programme, ensuring that remedial action plans are agreed with commissioners;	5.3 Other Applicable Local Standards / 7.2 Pathways	Specify importance of remedial action plans	SWG	Jan 2024-Feb 2025
Patient and Carer Engagement The SHT will ensure public and patient engagement (PPE) through: • User or user group representation at meetings	Service user and carer engagement The SHT will ensure service user/carer and public engagement through: • Service user or user group input at meetings, such as HCC business meetings;	5.3 Other Applicable Local Standards / 7.2 Pathways	Specify importance of engagement with charities and gathering service user feedback	SWG	Jan 2024-Feb 2025

• User involvement in service planning and development The SHT will promote user feedback and engagement with all healthcare providers.	• Service user involvement in service planning and development; • Engagement with local and national charities. The SHT will promote user feedback and engagement with LHTs. Regular service user feedback, at least every 3 years using appropriate feedback tools, should be gathered.				
Education and Research • The SHT will be able to provide practical training to all relevant clinical staff including junior doctors and nurses and other allied health professionals • Training for nurses should meet a recognised competency framework for nursing haemoglobinopathy patients. • All counsellors or healthcare professionals who counsel couples at risk of an affected	Education and research • The SHT must be able to provide access to appropriate and relevant local Trust training in sickle cell, thalassaemia and rare anaemia. This is for all relevant clinical staff including junior doctors, nurses and other allied health professionals involved in direct patient care; • Training for nurses should meet a recognised competency framework for nursing	5.3 Other Applicable Local Standards / 7.2 Pathways	Clarity of SHT responsibility and more succinct	SWG	Jan 2024-Feb 2025

pregnancy should have undertaken the relevant training. In order to deliver this service staff must be supported and trained to build capability for the consistent delivery of high quality, evidence based care for patients. This will be underpinned by robust clinical governance and an educational and training plan to embed learning and professionalism.	haemoglobinopathy service users.				
Transition	Transition	5.3 Other Applicable Local Standards / 7.2 Pathways	Updated with generic wording on Transition	SWG	Jan 2024-Feb 2025
• Transfusion laboratories must be aware of the special requirements of haemoglobinopathy patients and ensure that national guidance has been incorporated these into their transfusion guidelines and standard operating procedures.	Removed	5.3 Other Applicable Local Standards / 7.2 Pathways	Removed as not a requirement for SHTs	SWG	Jan 2024-Feb 2025

Access to a Comprehensive range of Clinical Specialists Experienced in Treating Haemoglobinopathy Patients	Additional services/clinical specialists added (inpatient and outpatient physiotherapy, Occupational Therapy, Dietetics, Benefits/social worker support, Maxillo-facial surgeons or tertiary dentists and Play therapy for paediatrics.).	5.3 Other Applicable Local Standards / 7.2 Pathways	More comprehensive list	SWG	Jan 2024-Feb 2025
None	Equitable service provision The SHT will work with both the HCC and LHTs to develop an understanding of the service needs of the population served through: • Regular assessment of characteristics within the SHT caseload, such as ethnicity, deprivation, cultural and linguistic differences; • Use of health equity audit (HEAT) in partnership with the relevant LHTs to assess issues or differences regarding access to services; • Gap analysis of healthcare needs and a plan to meet	7.2 Pathways	Highlight importance of equitable service provision	SWG	Jan 2024-Feb 2025

	need, agreed with HCC network members.				
None	Shared care arrangements Individual formal agreements should be in place with each LHT, depending on the capacity of each LHT to deliver aspects of the service, covering: • Delegation of annual reviews to the LHT; • New service user and annual review guidelines; • LHT management and referral guidelines; • NHR data collection; • Two-way communication of service user information between the SHT and LHT; • Access to MDT meetings; • Participation in network audits; • Joint clinics, where needed. Some LHTs may, with the agreement of the SHT, also provide some aspects of specialist care within the	7.2 Pathways	New section in template	SWG	Jan 2024-Feb 2025

	network (e.g. if there is specific surgical expertise within the Trust). This will be agreed on a Trust by Trust basis. A standard operating procedure should be agreed between the SHT and LHT(s) that clearly specifies indications for immediate transfer, early referral, routine referral and cases to refer for discussion in the HCC/SHT MDT.				
None	Clinical networks The Provider is required to actively participate in the HCC network to enable services to be delivered as part of a co-ordinated, combined whole system approach. SHTs will act as the lynchpin of a local network of haemoglobinopathy services, supporting and encouraging LHTs to take an active part in the HCC network to improve care pathway coordination	7.3 Clinical networks	New section in template	SWG	Jan 2024-Feb 2025

	and improve outcomes for service users. SHTs may wish to refer particularly complex cases or cases where learning has occurred via the HCC for discussion at the National Haemoglobinopathy Panel MDT.				