SCHEDULE 2 – THE SERVICES

A. Service Specifications

1. Service name	Specialist Haemoglobinopathy Services (adults and children) • Haemoglobinopathy Coordinating Centres
2. Service specification number	170125S
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** This service specification applies to providers commissioned as Haemoglobinopathy Coordinating Centres (HCCs). HCCs are responsible for coordinating clinical networks that deliver specialist care for service users of all ages with sickle cell disease (SCD), thalassaemia and rare inherited anaemias (RIAs) including those requiring transfusion and/or chelation therapy.
5.2	**Minimum population size** HCCs are provider organisations within clinical networks that serve agreed geographical areas. Demographics vary across the country and as such population sizes will vary. This specification should be read in conjunction with service specification 170126S Specialist Haemoglobinopathy Teams.
6.	**Service aims and outcomes**
6.1	**Service aims** HCC networks, through innovation and technology, strive to improve equity of access to healthcare. They also aim to ensure equitable access to research and newly approved therapies for all individuals within their network geography. HCCs work to ensure that multi-disciplinary expertise is extended to all service users within their network footprint through expert training, clinical Multi-Disciplinary Teams (MDTs) and other innovative solutions. The overall aim of the service is to reduce levels of morbidity, mortality and health inequalities and improve the outcomes and experience of all haemoglobinopathy service users.
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

The quality of specialised services is monitored through Specialised Services Quality Dashboards (SSQDs), which normally comprise a range of quality outcomes (including clinical outcomes) and quality metrics which are supported by regular data collections. SSQDs are available on NHS England's website at https://www.england.nhs.uk/specialised-commissioning-document-library/.

Included in the range of metrics that support understanding of the quality of the HCC network are:

- Proportion of service users with sickle cell within the HCC network who have had a serious adverse event (as defined in the National Haemoglobinopathy Registry) in the reporting period
- Proportion of service users with thalassaemia or RIA within the HCC network who have had a serious adverse event (as defined in the National Haemoglobinopathy Registry) in the reporting period

HCCs must also support local providers to register all service users on the National Haemoglobinopathy Registry (NHR) and submit complete, accurate and timely returns.

7. Service description

7.1 Service model

HCCs coordinate the networked provision of healthcare by Specialist Haemoglobinopathy Teams (SHTs) and non-specialist Local Haemoglobinopathy Teams (LHTs). They receive dedicated funding to fulfil their responsibilities outlined below.

SHTs provide clinical services, including specialist interventions, and work with LHTs to enable equitable access for their population to high standards of care across the network.

The National Haemoglobinopathy Panel (NHP) supports HCCs to provide expert advice on options for individuals with complex needs living with SCD, thalassaemia or rare inherited anaemias. The NHP also supports decision making on novel treatments, improving access to interventions and clinical trials, as set out in its Terms of Reference.

	HCC networks must provide multi-disciplinary expertise to the NHP to ensure complex cases and cross-organisational issues/risks are discussed and learning is shared. One, or several providers in partnership, take on the role of the HCC for the network. An HCC must also have been commissioned as an SHT. The number of SHTs and LHTs within an HCC's network footprint will vary depending on geography and disease prevalence. Each HCC network will provide strategic oversight for the whole lifetime pathway of care. HCCs also coordinate across multiple providers, including liaising with the NHS Sickle Cell and Thalassaemia Screening Programme. This is to ensure timely referrals for babies into the care pathway.
7.2	**Pathways** <u>Overall patient pathway</u> Haemoglobinopathies and rare inherited anaemias are lifelong conditions and service users will access on-going routine and specialist care throughout their lifetime, delivered as close to their home as possible. Whilst these conditions are rare and sometimes complex, the routine monitoring and treatment can be effectively managed using networked pathways and protocols with HCC oversight. <u>Specialised patient pathway</u> Specialist haemoglobinopathy services include all care provided by SHTs including inpatient care where the cause of admission is related to haemoglobinopathy. The service includes outreach when delivered as part of a provider network. All care must be linked to and supported by an SHT and overseen by the relevant HCC. LHTs and SHTs have responsibility to implement HCC network approved guidance, protocols, pathways and participate in agreed audit, trial, and data reporting. HCCs must support SHTs to ensure training and protocols for the acute care of SCD and thalassaemia are available for all Emergency Departments and acute teams in the network area. HCCs must support the equitable access to urgent or emergency interventions such as exchange transfusions for critically unwell service users for their networks. Clear escalation policies should be in operation detailing the process for escalation and transfer if necessary, particularly where high dependency units are centralised (e.g. paediatric intensive care units). HCCs should ensure equitable access to specialist or complex interventions or clinics within their network e.g. supra specialist surgery, joint specialist medical or paediatric clinics. Where interventions are not available within the network, clear policies should be in place for equitable access to services outside of the network e.g. stem cell transplant.

	HCCs should work in partnership with NHS Blood and Transplant to support access to transfusion expertise where needed and ensure adequate supplies of blood with special requirements are available in a timely manner to meet service user needs. <u>Transition</u> HCCs should have oversight on appropriate arrangements made by SHTs to ensure seamless transition of care from paediatric to adult services across the network.
7.3	**Clinical Networks** All Providers are required to participate in the HCC network to enable services to be delivered as part of a co-ordinated, combined whole system approach. HCCs are responsible for escalating any issues relating to lack of engagement to relevant commissioners. Indicators and metrics of HCC network performance come from three principal sources: 1. Generic indicators of a well set up, well-functioning network, which must be in place: • There is an appropriate network management team in post as outlined in section 7.4 with the skills to deliver the specification. • The Network Business Meeting/Board meets a minimum of two times per year and minutes, actions and risks are recorded. Representatives from SHTs and LHTs are included. • There are IT facilities in place that enable communication across the network, supporting image transfer and remote participation in the MDT. • There is an agreed plan for Patient and Public Voice (PPV) engagement. • There is an analysis of the service needs of the population served by the network, a gap analysis and a plan, agreed with network members, to meet these needs. This should include an assessment of population characteristics such as ethnicity and deprivation, particularly regarding access to services. Use of health equity audit (HEAT) should be encouraged across SHT and LHTs. • There is an analysis of workforce requirements and a plan, agreed with network members, to meet these requirements. • There are arrangements (for example honorary contracts) that enable workforce flexibility between providers within the network. • There is an analysis of education and training needs and an annual network education and training plan agreed with network members. • There is an analysis of the network's data and information needs and a plan, agreed with network members, to meet these needs. • There is a network agreed audit and research and development strategy, including access and participation in clinical trials. • There are network agreed service user pathways, procedures, and protocols. • An annual report is produced and submitted to commissioners, detailing the network's activities, accounts and delivery against the agreed plans. • HCCs must report on the activity and finance related to the specialised budget and ensure that the funding is used for agreed HCC activities.

2. Nationally agreed metrics and outcomes for all HCC networks:

   These are included in the SHT service specification and are delegated across the network system. Networks must have access to provider data, for example through the NHR, for oversight and assurance of performance.

3. The HCC network's individual locally agreed annual workplan:

   This should include metrics for each deliverable. The Network Board should agree the annual workplan with relevant commissioners.

Resources: the HCC network's role in stewardship of resources across the whole pathway and minimising unwarranted variation

- Develop an approach to optimising efficient use of resources across the whole pathway.
- Reduce unwarranted variation in pathways and processes that lead to inefficiencies.
- Support network-wide sharing of innovative approaches to care.
- Work with other related HCC networks, SHTs and LHTs, flexing use of resources to find efficiencies, target resources for best effect and share insight and experience.
- Support the work of the national Haemoglobinopathies Clinical Reference Group by implementing national commissioning products.

Workforce: the HCC network's role in ensuring flexible, skilled, resilient staffing

- Assess future workforce needs for provision of haemoglobinopathy services across the network considering projected demand.
- Support providers to develop and implement innovative and extended roles for non-medical staff groups, through training and development and network wide policies and procedures.
- Support providers to actively recruit staff who are representative of the local service user populations served.
- Assess training needs for the network (including baseline skills and network maturity assessment). This should include training in Equality, Diversity and Inclusion and consideration of Cultural Competency to meet the needs of service users with cultural and linguistic differences.
- Develop and agree a network training plan that meets the needs of the network both in the delivery of care and in the functioning of the network.
- Agree with commissioners and providers how the planned training will be resourced and delivered.
- Monitor delivery and assess the effectiveness of the agreed training.

Quality: the HCC network's role in improving quality, safety, experience & outcomes

- Establish and maintain systems for the collection, analysis and reporting of key indicators of outcomes, quality of care and service user experience.

- Ensure that outcomes can be analysed by service user characteristics (age, sex, ethnicity, deprivation score) to examine differences between groups.
- Monitor compliance of reporting to the NHR to understand any gaps and issues.
- Provide commissioners with local information, data, and intelligence to support performance monitoring of the network.
- Manage risks to the delivery of the network's annual work programme.
- There are monthly network Specialist MDT Meetings for the consideration of very complex service users, with onward referral routes to the NHP. These include Morbidity and Mortality meetings to share learning across the network, and with the NHP as appropriate. SHTs and LHTs are responsible for sharing of information including reviews of deaths and complications, Patient Incident Response Framework (PSIRF) trends and incidents and never events as soon as possible.
- Ensure the provision of high-quality information for service users, families, staff, and commissioners, standardised across the network.
- Comparative benchmarking of services, including Patient Reported Outcome Measures (PROMS) Patient Reported Experience Measures (PREMS) and complications to improve service quality, experience, and effectiveness.

Risk management and risk sharing

HCC networks do not manage risk independently but within a system of national, regional and system level arrangements. Networks support risk identification, assessment, mitigation and may facilitate any agreed response.

SHTs and LHTs are responsible for sharing of information as soon as possible and transparency.

Information sharing, collaborative working and knowledge transfer

HCCs will collaborate with their network of providers, commissioners and other HCCs to develop information, guidance, protocols, and pathways that include but are not limited to the following:

- Service user information, support, training, and self-management;
- Each network should have a comprehensive set of agreed joint referral and care protocols;
- Insights from PPV representatives, partners from relevant charities and community groups to gain insight into any reluctance or barriers to accessing services;
- Service user involvement in service development and improvement across the network;
- Contact information, referrals, and arrangements for 24/7 access to specialist advice for complex cases for service users and healthcare professionals;
- Access to the NHP for discussion of rare or very complex cases or for the consideration of novel therapies;
- Individualised care plans and alert cards etc;
- Life course care (new-born screening; family centred care; transition; pregnancy; reproductive health; end of life);

	• Prevention and screening including Trans Cranial Doppler (TCD) screening and screening for chronic complications; • Staff education and training; • Routine outpatient monitoring and annual review; • Planned day case and inpatient care; • Emergency care; • Treatment and interventions; • Management of acute and chronic complications; • Chronic pain management; • Co-ordination of supra-specialist services such as sickle liver disease, sickle hip services, bone marrow transplantation and cellular therapies, specialist pain management, among others, to ensure all eligible service users have access; • Regular audits and benchmarking of clinical and operational service delivery to inform service improvement across the network; • Research and development. In addition, HCCs should work with providers within the network to ensure: • An identified TCD screening lead is in place who has the responsibility for ensuring the network has adequate numbers of appropriately trained practitioners and a record is kept of the number of TCDs performed, together with the number of abnormal TCDs; • Nationally agreed quality assurance requirements are met including TCD, MRI and quality/peer review programmes; • There is a mechanism in place for providing advice on emergencies that occur outside of normal working hours; • Collaborate with other HCCs across the country as necessary for specialist clinical advice in areas of low prevalence; • Educational activities within the network are linked. **Transformation: the HCC network's role in planning sustainable services that meet the needs of all service users** • Regularly review HCC network configuration, capacity, and compliance with standards, advising and agreeing a plan with commissioners to assure sustainable services that meet the needs of all service users. • Work in partnership with ICBs and NHSE to develop a strategic approach to improving haemoglobinopathy pathways, including the delivery of an optimal configuration of haemoglobinopathy services within the geography. • Develop, implement and monitor new models of care. • Support the early and systematic adoption of innovation and research across the network. • Ensure newly approved novel therapies are made available to eligible service users within the network footprint.
7.4	**Essential Staff Groups** Each HCC network receives dedicated funding for a team to support its work that provides clinical leadership, management and administrative support. This should include:

- A clinical lead and deputy clinical lead - consultant physicians able to provide care directly, and to advise and support colleagues at other providers and in other services;
- Nursing leadership to support network nursing staff and relevant education activity, covering all aspects of specialist haemoglobinopathy care including sickle cell disease, thalassaemia and rare anaemias;
- A network manager;
- Data/administrative support to link with data managers and relevant others such as general managers across the network;
- PPV representatives;
- A dedicated pharmacist to manage the pharmaceutical needs of service users and provide expert advice across the network;
- HCC networks should also include additional external stakeholders, including partners from relevant charities.

Roles such as administration and analytical support may be appropriately combined across HCC networks.

7.5 Essential equipment and/or facilities

An HCC must also be an SHT – see service specification 170126S Specialist Haemoglobinopathy Teams for relevant essential facilities.

7.6 Interdependent Service Components – Links with other NHS services

Interdependent Service	Relevant Service Specification/Standards	Proximity to service
Specialist Haemoglobinopathy Teams	https://www.england.nhs.uk/publication/specialist-haemoglobinopathy-services-specialist-haemoglobinopathy-teams/	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 https://www.england.nhs.uk/commissioning/spec-services/npc-crg/ 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 • Red blood cell specifications for patients with hemoglobinopathies: a systematic review and guideline https://pubmed.ncbi.nlm.nih.gov/29697146/ • 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 UKFHD Quality Standards for Health Services for People with Haemoglobin Disorders: • https://haemoglobin.org.uk/3d-flip-book/qs-haemoglobin-disorders-v5-2-pdf/ Midlands Specialised Commissioning (Acute and Pharmacy) Health Inequalities Strategy • https://www.england.nhs.uk/midlands/wp-content/uploads/sites/46/2024/02/Specialised-Commissioning-Acute-and-Pharmacy-Health-Inequalities-Strategy-FINAL-PDF-1.0.pdf NHS England's statement on information on health inequalities (duty under section 13SA of the National Health Service Act 2006) • https://www.england.nhs.uk/long-read/nhs-englands-statement-on-information-on-health-inequalities-duty/#appendix-1-information-on-health-inequalities-to-be-collected-analysed-and-published

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

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

Publication number: 170125S

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. Content structure based on national network specification template.	Throughout	A new service specification template was published in 2022	SWG	July 2023-Feb 2025
This service specification covers Haemoglobinopathy Coordinating Centres (HCC) to support the provision of specialist and non-specialist haemoglobinopathy services to adults and children and to provide expert opinion and	HCCs coordinate the networked provision of healthcare by Specialist Haemoglobinopathy Teams (SHTs) and non-specialist Local Haemoglobinopathy Teams (LHTs).	1.1 Prescribed Specialised Service / 7.1 Service model	To clarify that HCCs do not provide direct patient management	SWG	July 2023-Feb 2025

management for complex patients.					
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 HCC provides a coordinated leadership function, supporting Specialist Haemoglobinopathy Teams (SHTs) in the delivery of clinical care. Overall, the model of care is about the effectiveness of the SHT and HCC in delivering equity irrespective of where patients live through: Governance to improve: • access to services • access to expertise Leadership to improve: • patient experience • outcomes HCCs are responsible for coordinating, supporting and promoting a system-wide	HCC networks, through innovation and technology, strive to improve equity of access to healthcare. They also aim to ensure equitable access to research and newly approved therapies for all individuals within their network geography. HCCs work to ensure that multi-disciplinary expertise is extended to all service users within their network footprint through expert training, clinical Multi-Disciplinary Teams (MDTs) and other innovative solutions. The overall aim of the service is to reduce levels of morbidity, mortality and health inequalities and improve the outcomes and experience of all haemoglobinopathy service users.	1.2 Aim of the service / 6.1 Service aims	Amended to make more succinct and reflect feedback from clinicians and service users on key aims	SWG	July 2023-Feb 2025

networked approach to the delivery of haemoglobinopathy services. HCCs will free up SHTs' time and clinical resources by providing support for the administrative aspects of networked care within its geographical area. This structure will support and strengthen the network concept; improve sharing of best practice and address systems learning; and reduce unwarranted variation. The HCC will provide additional coordination, training and clinical leadership support for existing networking arrangements. In order to be a HCC a trust must have, and comply with, a contract to provide SHT services with NHS England. Whilst the HCC's role is primarily that of a network coordinator, HCCs must demonstrate that they have the clinical expertise to lead the development of their					

networks and HCCs must be equipped to provide specialist advice. Therefore, HCCs are required to discharge this role in addition to their role as a provider of direct patient care through their role as an SHT. The purpose of the specification is to outline the responsibilities of HCCs and the relationships that need to be in place with SHTs, the wider health economy and patients.					
The diagram below describes the network and relationship between the teams. Depending on location and prevalence, a HCC could be responsible for providing network support for one, two or several SHTs.	*Diagram removed* One, or several providers in partnership, take on the role of the HCC for the network. An HCC must also have been commissioned as an SHT. The number of SHTs and LHTs within an HCC's network footprint will vary depending on geography and disease prevalence.	1.3 Service Description	SWG considered diagram to depict an incorrect hierarchical relationship between network providers	SWG	July 2023-Feb 2025
The HCC together with local network arrangements will be responsible for:	HCCs must also support local providers to register all service users on the National	2.3 Roles and Responsibilities / 6.2 Outcomes	The NHR is now a non-consented registry	SWG	July 2023-Feb 2025

• Supporting local providers to register all consented patients on the National Haemoglobinopathy Register and demonstrating that resources invested are delivering effective network arrangements	Haemoglobinopathy Registry (NHR) and submit complete, accurate and timely returns.				
HCCs will support local workforce planning and will be able to escalate this to a national level, including the national haemoglobinopathies Clinical Reference Group… The HCC will oversee and support the production of a training and development plan for all healthcare staff involved in the delivery of care for haemoglobinopathy patients in its network. The responsibility for resourcing appropriate training for healthcare staff remains with their employing organisations. Concerns about staff training across a network should be escalated through the network and to the HCC for exploration and resolution	• There is an analysis of workforce requirements and a plan, agreed with network members, to meet these requirements. • There are arrangements (for example honorary contracts) that enable workforce flexibility between providers within the network. Workforce: the HCC network's role in ensuring flexible, skilled, resilient staffing • Assess future workforce needs for provision of haemoglobinopathy services across the network considering projected demand. • Support providers to develop and implement	2.3 Roles and Responsibilities / 7.3 Clinical Networks	Additional detail on the HCC's responsibility with regards to workforce for clarity	SWG	July 2023-Feb 2025

with Royal Colleges / General Medical Council (GMC) / Nurse and Midwifery Council (NMC) / Health Education England (HEE) / commissioners.	innovative and extended roles for non-medical staff groups, through training and development and network wide policies and procedures. • Support providers to actively recruit staff who are representative of the local service user populations served. • Assess training needs for the network (including baseline skills and network maturity assessment). This should include training in Equality, Diversity and Inclusion and consideration of Cultural Competency to meet the needs of patients with cultural and linguistic differences. • Develop and agree a network training plan that meets the needs of the network both in the delivery of care and in the functioning of the network. • Agree with commissioners and providers how the				

	planned training will be resourced and delivered. • Monitor delivery and assess the effectiveness of the agreed training.				
The HCC will offer additional clinical specialist support and specialist advice for the management of very complex patients as part of the regional MDTs for non-urgent cases or through the provision of telephone or email advice for outpatient / inpatient care. Complex patients may occasionally (and by exception) have to attend the HCC for review and discussion of disease modifying or experimental therapy or to attend supra-specialist clinics (e.g. pulmonary hypertension, neurology). Exceptionally, it might be necessary to transfer patients for care.	There are monthly network Specialist MDT Meetings for the consideration of very complex service users, with onward referral routes to the NHP… HCCs will collaborate with their network of providers, commissioners and other HCCs to develop information, guidance, protocols, and pathways that include but are not limited to the following: • Contact information, referrals, and arrangements for 24/7 access to specialist advice for complex cases for service users and healthcare professionals; In addition, HCCs should work with providers within the network to ensure: • There is a mechanism in place for providing advice	2.3 Roles and Responsibilities / 7.3 Clinical Networks	To provide clarity on the role of the HCC, as distinct from the SHT, with regards to access to specialist advice	SWG	July 2023-Feb 2025

	on emergencies that occur outside of normal working hours; • Collaborate with other HCCs across the country as necessary for specialist clinical advice in areas of low prevalence;				
National Haemoglobinopathy Panel	The National Haemoglobinopathy Panel (NHP) supports HCCs to provide expert advice on options for individuals with complex needs living with SCD, thalassaemia or rare inherited anaemias. The NHP also supports decision making on novel treatments, improving access to interventions and clinical trials, as set out in its Terms of Reference.	1.5 National Haemoglobinopathy Panel / 7.1 Service model	More concise, recognising that there is a separate ToR for the NHP	SWG	July 2023-Feb 2025
National Haemoglobinopathy Registry	None	1.6 National Haemoglobinopathy Registry	There is a separate ToR for the NHR	SWG	July 2023-Feb 2025
All care should be linked to and supported by a Haemoglobinopathy Coordinating Centre (HCC).	All care must be linked to and supported by an SHT and overseen by the relevant HCC. LHTs and SHTs have responsibility to implement HCC network approved guidance, protocols, pathways	2.1 Care Pathway / 7.2 Pathways	Additional clarity on responsibility of providers within the HCC network	SWG	July 2023-Feb 2025

	and participate in agreed audit, trial, and data reporting.				
Referral	None	2.2 Referral	Content moved to SHT service specification	SWG	July 2023-Feb 2025
This specification applies to: all children and adults with Sickle Cell Disease and Thalassaemia and other inherited anaemias requiring transfusion and/ or chelation therapy such as Blackfan Diamond anaemia, pyruvate kinase deficiency and congenital sideroblastic anaemia amongst others. The service outlined in this specification is for patients ordinarily resident in England*; or otherwise the 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).	This service specification applies to providers commissioned as Haemoglobinopathy Coordinating Centres (HCCs). HCCs are responsible for coordinating clinical networks that deliver specialist care for service users of all ages with sickle cell disease (SCD), thalassaemia and rare inherited anaemias (RIAs) including those requiring transfusion and/or chelation therapy.	3.1 Population covered by this specification / 5.1 Population Covered	New template guidance and more concise	SWG	July 2023-Feb 2025

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.					
In England there are about 1,500 patients with thalassaemia and 15,000 with SCD and circa 1,000 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. Nearly all SCD affected children born in England, and the majority with thalassaemia, will be identified by the NHS Sickle Cell and Thalassaemia antenatal and neonatal Screening programme. Other new patients may present through migration or late diagnosis. The patient population is unevenly	HCCs are provider organisations within clinical networks that serve agreed geographical areas. Demographics vary across the country and as such population sizes will vary.	3.2 Understanding Local Population Needs / 5.2 Minimum population size	New template and prevalence data included in SHT service specification	SWG	July 2023-Feb 2025

distributed through the country, making equity of access a priority. Patients with rarer 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 are unknown but expected to be relatively small. 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 Services will need to develop to meet the needs of their local populations. This may mean using outreach and technology to share expertise. The increasing life expectancy of individuals with these					

conditions means that the overall prevalence will increase and services will 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.					
Quality Statement	Links to other key documents	4.1 Quality Statement / 7.9 Links to other key documents	New template and updated evidence	SWG	July 2023-Feb 2025
Indicators include…	Outcomes	4.2 Indicators include / 6.2 Outcomes	New template	SWG	July 2023-Feb 2025
None	Transition HCCs should have oversight on appropriate arrangements made by SHTs to ensure seamless transition of care from paediatric to adult services across the network.	7.2 Pathways	Outline responsibility of HCC with regards to transition	SWG	July 2023-Feb 2025
None	All Providers are required to participate in the HCC network to enable services to be delivered as part of a co-	7.3 Clinical Networks	Additional clarity on responsibility of providers within the HCC	SWG	July 2023-Feb 2025

	ordinated, combined whole system approach. HCCs are responsible for escalating any issues relating to lack of engagement to relevant commissioners.		network and escalation arrangements		
None	Generic indicators of a well set up, well-functioning network, which must be in place…	7.3 Clinical Networks	To set out HCCs' responsibilities with regards to developing plans and reporting	SWG	July 2023-Feb 2025
None	Essential Staff Groups	7.4 Essential Staff Groups	New template and to specify which roles the HCC team should include.	SWG	July 2023-Feb 2025