Health Services for People with Haemoglobin Disorders

St George's University Hospitals NHS Foundation Trust

Visit Date: 21st March 2025

Report Date: 24th June 2025

Contents

Introduction

This report presents the findings of the review of St George's University Hospitals NHS Foundation Trust that took place on 21st March 2024.

The purpose of the visit was to review compliance with the Health Service for People with Haemoglobin Disorders Quality Standards Version 5.2, November 2023 which were developed by the Forum for Haemoglobin Disorders (UKFHD). The peer review programme and visit were organised by the Nursing and Urgent Care Team (NUCT) at NHS Midlands and Lancashire (ML). The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

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

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

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

The report reflects the situation at the time of the visit. The text of the report identifies the main issues raised during the course of the visit. Any immediate risks identified will include the Trust and UKFHD/NUCT ML response to any actions taken to mitigate against the risk. Appendix 1 lists the visiting team that reviewed the services in St George's University Hospitals NHS Foundation Trust health economy. Appendix 2 contains the details of compliance with each of the standards and the percentage of standards met.

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

- St George's University Hospitals NHS Foundation Trust
- NHS England, London Region
- South West London Integrated Care System

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. Many can be tackled by the use of appropriate service improvement approached; some require commissioner input. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place and monitoring their implementation, liaising, as appropriate, with other commissioners, including commissioners of primary care. The lead commissioners in relation to this report are NHSE London Region and South West London Integrated Care Board.

About the UKFHD and NHS ML

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

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

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

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

Acknowledgments

The UKFHD and NHSML would like to thank the staff and service users and carers of the St George's University Hospitals NHS Foundation Trust health economy for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks, are also due to the visiting team and their employing organisations for the time and expertise then contributed to this review.

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Review Visit Findings

St George's University Hospitals NHS Foundation Trust

Trust-wide General Comments

This review looked at the health services provided for children, young people, and adults with haemoglobin disorders at St George's University Hospitals NHS Foundation Trust (SGUH). In total the trust served approximately 700 patients with Haemoglobin Disorders, mostly sickle cell disorders (SCD). During the visit the reviewers attended the St George's University Hospital site and visited emergency departments, assessment units and wards; they met with patients and with staff providing services for the local health economy.

St George's University Hospitals NHS Foundation Trust was a teaching hospital with over 1000 beds and a catchment population of about 1.3 million across South-West London. The adult and paediatric Specialist Haemoglobinopathy Team (SHT) provided a service to the regions of South West London and South West Thames. There were six local haemoglobinopathy teams supported by SHT at SGUH.

St George's University Hospitals NHS Foundation Trust was designated by NHS England as a 'Specialist Haemoglobinopathy Team' within the Sickle Cell Disease West London Haemoglobinopathy Coordinating Centre (HCC), in partnership with Imperial College Healthcare NHS Trust (ICHT) and London North West University Healthcare NHS Trust (LNW). Furthermore, it was part of the Thalassaemia HCC for London, South Central, and South West in collaboration with University College London Hospitals NHS Foundation Trust, Imperial College Healthcare NHS Trust, and London North West University Healthcare NHS Trust.

West London HCC, Thalassaemia HCC, and National Haemoglobinopathy Panel (NHP) MDT meetings were held monthly. Additionally, the West London HCC and Thalassaemia HCC conducted adverse event MDTs every three months.

Some issues in this report relate specifically to the Trust as a whole and have been included in the Trust-wide section of the report. Other issues that were the same for both the adult service and the children and young people service have been repeated in each section of the report.

Trust -wide Good Practice

Trust-wide Good Practice – children and young people

1. A joint clinic between the SHT and the respiratory team was held which provided a holistic approach to seeing patients living with a haemoglobin disorders who also had respiratory conditions.
2. The CNS and psychology service had found innovative ways of engaging with patients. Some engagements were held virtually so that CYP further away and cared for in the LHTs could join.
3. All children and young people living with SCD, Thalassaemia or RIA who may need to attend the PED had clinical alerts in place on their care records.
4. The TCD service was very flexible and accommodating. Reviewers heard of instances whereby children could have their TCD undertaken at weekends to avoid further school absence.
5. One of the parents had written and published a book A-Z of Sickle Cell disease explaining key aspects of the disease and investigations for younger children. The SHT had been able to gain charitable funding to enable copies of the book were available for children.

Trust-wide Good Practice – adults

1. There was an excellent Psychology Service. A psychologist attended the ward round which helped to establish psychology support as the norm for patients rather than something unusual. They worked with GPs to support with opiate prescriptions and care planning and offered both group and individual therapy sessions

for patients living with red blood cell conditions. In addition to individual support, the team ran a monthly online support group to provide a safe and accessible space where patients with sickle cell and thalassaemia could share experiences and connect with others.

2. There was a specialist pain management clinic, co-led by a Consultant in Pain Management and a Clinical Psychologist. Joint self-management assessments with a clinical psychologist and physiotherapist were offered as a multidisciplinary approach to pain management.

3. The review team observed clear and meaningful engagement from trust senior management who collaborated closely with clinical teams to understand any risk, develop business cases, and identify funding in response to patient need.

Trust -wide Immediate Risk

1. **Paediatric Specialist Haemoglobinopathy Team (SHT) Consultant Workforce** [1]

   Reviewers were extremely concerned for the clinical safety and clinical outcomes of children and young people with haemoglobin disorders cared for by the trust as there were insufficient consultant staff with specialist experience in the care of children with haemoglobin disorders on site to provide scheduled care, and at the time of the visit, unscheduled care was supported by Imperial College Healthcare NHS Trust (ICHT).

   The SHT had two consultant paediatric haematologists, with some support from a consultant paediatrician with a specialist interest in haematology, who provided speciality care for all non-malignant haematology including the specialist care of approximately 250 children and young people with haemoglobin disorders. Fifty percent of these children and young people received their care from six local haemoglobinopathy teams who required access to specialist care and advice from the SGUH as their SHT.

   At the time of the visit, due to working patterns there was no onsite cover by a consultant paediatric haematologist or consultant paediatrician with a specialist interest in haematology for scheduled or unscheduled care on Mondays. There had not been any haematology trainees rotating through the paediatric service since 2019 and the clinical nurse specialist only worked Tuesday to Thursdays. The consultant paediatrician with a specialist interest in haematology was also about to take a career break for three months.

   The trust had been unsuccessful in appointing to the vacant consultant paediatric haematologist post, and from discussions with trust staff the last time the post was advertised was May 2024, and the reasons for not readvertising since this time were not clear.

   The agreed SLA between Imperial College Healthcare NHS Trust and St George's University Hospitals NHS Foundation Trust (SGUH) to provide temporary 24/7 telephone advice to the Trust had been due to cease at the end of February 2025, however the SLA had been extended until April 2025 on condition that the Trust agreed how to address the service risk.

   The risk to children and young people had been identified and documented on the Trust risk register since 2023 but apart from the interim emergency arrangements with ICHT, as a result of multiple consultant staff absences, the trust had not agreed a strategic plan to address the risk and at the time of the visit were considering a range of options.

[1] The immediate risk is included in the Trust wide section as well as in the Paediatric SHT section of the report.
See Appendix 3 for Trust and UKFHD Responses

Trust -wide Serious Concerns

Text Trust-wide Serious Concern – children and young people

1. **Access to Apheresis**

   Reviewers were concerned about the provision of apheresis at the Trust and the pathway for children and young people to access an elective automated red cell exchange programme (aRCE). At the time of the visit only young people over the age of 13 years were now accepted to receive aRCE at the Trust although there was an established adult service. This had resulted in children under the age of 13 years, who needed to start an exchange transfusion programme being referred to another centre.

Trust -wide Concern

1. **Transition Pathway**

   The pathway for young people transitioning to adult care was of concern for a number of reasons. *See adult and children's concern sections of the report.*

Trust-wide Concern – children and young people

1. **Clinical Nurse Specialist Workforce**

   The reviewers were concerned that the service had insufficient CNS staffing for the number of children under the care of SHT. At the time of the visit CNS cover was only available Tuesdays to Thursdays and there was no cover for absences to provide scheduled or unscheduled care.

2. **Access to Psychology**

   Access to psychology was insufficient to meet the needs of the 245 children and their families cared for by the SHT and to provide support for those children, young people and families receiving shared care in the LHTs.

3. **Training and Competence Framework**

   Due to the shortages in workforce across the SHT, they had limited time to provide training to ED and nursing staff on wards and areas to which children and young people were usually attended or were admitted. Some ED staff and ward nurses had received training in haemoglobinopathies, but a formal competence framework and process for assessing knowledge and ongoing monitoring was not yet in place.

4. **Data and administrative support**

   The SHT had only 1 WTE secretary shared between haematology, oncology & cardiology and the secretary was leaving at the end of March 2025 and consultant and nursing staff were spending clinical time on administrative tasks, including arranging future blood test appointments when patients attended clinics. At the time of the visit here was no support for data collection, audits or data for NHR. Reviewers were told that there was funding for a 0.4WTE data support role, but at the time of the visit recruitment to this post had not commenced.

Trust-wide Concern – adults

1. **Lead Nurse Funding –** A lead nurse had been appointed to commence in post from April 2025 however this was an 18-month fixed term contract. The review team were concerned that with the growing service this post needed to be sustainable. Reviewers however were reassured that the General manager was aware of the risk and was working to establish the post in the long term.

2. **Commissioning** - Projects such as the adult psychology resource, complimentary therapy, and social prescribing were funded NHSE Sickle Cell and Thalassaemia Community Project which was provided on a 2-

year pilot. Although there is ICB commitment to continue, the review team were concerned that the political climate specifically around shifting ICB and NHSE finances may disrupt such highly valued services.

Views of Service Users and Carers

Support Group available for patients and carers	Y/N
Sickle Cell Disorder – Children and Young People	
Thalassaemia – Children and Young People	
Sickle Cell Disorder- Adults	Y
Thalassaemia – Adults	Y

The visiting team organised focus groups prior to the visit but did not meet with adults living with a sickle cell disorder or living with thalassaemia, or any families caring for children and young people living with a sickle cell disorder or living with thalassaemia prior to the visit. Unfortunately, on the day of the visit there were no children or young people receiving treatment on the day unit who may have been able to meet the visiting team. The visiting team were able to meet with three adults living with a haemoglobin disorder on the day unit.

The review team would like to thank those who met with the visiting team for their openness and willingness to share their experiences.

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Specialist Haemoglobinopathy Team (Children and Young People Services)

General Comments and Achievements

The Paediatric Specialist Haemoglobinopathy Team (SHT) based at St George's Hospital provided care to children and families from birth to 18 years of age residing across SW London and the SW Thames Region.

This was a hard working committed team who were working above and beyond their roles, despite significant staffing and resource challenges, particularly over the 18 months before the peer review visit.

The team had two consultant paediatric haematologists with a total number of 14 PAs for the delivery of all non – malignant haematology and there was also support from a consultant paediatrician with a specialist interest in haematology. A CNS post had been established in 2019 and at the time of the visit 0.76 WTE post was in place with 0.24WTE vacancy. The SHT had clinical psychology support totalling 0.6WTE comprising of 0.4 WTE for patients with living with a haemoglobin disorders and 0.2WTE allocated for cognitive assessments and whilst both these posts had been a great improvement for patients, the time available was insufficient to meet the needs of the number of children and their families cared for by the SHT. There was no junior doctor support for the service except from the general paediatric team for inpatients. There was no support for data collection, audits or data for NHR, although reviewers were told that there was funding for a 0.4WTE data support post. The paediatric pain team was in operation Monday to Friday and were available to see children and young people living with haemoglobin disorders who were admitted with acute pain associated with a vaso-occlusive crisis.

The acute staffing shortage since November 2023 had led the trust to seek external support for the service for 24/7 advice, initially provided by the Evelina London Children's Hospital (ELCH) and subsequently the paediatric haematology service based at St Mary's Hospital (ICHT). A small number of children with complex sickle cell disease also had their care transferred to the SHTs based at Kings College Hospital NHS Foundation Trust (KCH) and ELCH. At the time of the visit, ICHT was continuing to provide out of hours support to the service (with an SLA in place until April 2025) whilst the Trust Senior Leadership Team agreed a long term plan for safe and sustainable delivery of the service.

Newborn screening results were received centrally for the network at SGUH. If the child resided in a borough where there was a community team they would see the family otherwise the SGUH CNS would discuss the results and provide early support for families.

Medical care was provided in collaboration with named consultants for shared care in the local haemoglobinopathy teams (LHTs). The Trust reported that there had been a high level of patient mobility, particularly within the South Thames region, as well as an increased number of new arrivals from overseas in recent years. The linked LHTs were low prevalence areas with relatively small numbers of children and young people living with a haemoglobin disorder. The CNS and psychologist based at SGUH provided support for all families across the network and endeavoured to provide as equitable a service as they could with their available time. Additional support was available from various haemoglobinopathy community services in some London boroughs but not others and for those residing in Surrey and Sussex. The split of care between the SHT team at SGUH and the LHTs varied depending on the LHT and patient complexity.

The service was supported by tertiary paediatric services including general surgery, paediatric surgical sub-specialities (e.g. urology, ENT, orthopaedics) and intensive care, sitting within the South Thames paediatric network. There were dedicated paediatric radiology services and transcranial doppler scanning was provided by the vascular laboratory. Most paediatric medical sub-specialities were available on-site with renal and cardiology specialist input supported by ELCH and those requiring specialist hepatology or neurovascular input were referred to KCH.

Prior to the establishment of haemoglobinopathy co-ordinating centres (HCCs), the paediatric service had worked collaboratively with the South Thames Sickle Cell & Thalassaemia Network (e.g. on joint guidelines). Due to patient

geography and interlinked paediatric services operating in South/South West Thames networks they had maintained clinical links with those centres, particularly Croydon. Similarly, for geographical reasons, they had continued to provide tertiary care to a number of children from Frimley Park Hospital which was part of the Thames Valley HCC.

Feedback from LHTs

The visiting team met with representatives from the LHTs based at Ashford and St Peter's Hospital NHS Foundation Trust, Epsom and St Helier's University Hospital NHS Trust and Kingston and Richmond NHS Foundation Trust

They all commented that it had been difficult over the last couple of years to access general support and access to emergency care at SGUH. The CNS at SGUH had been able to provide some support to the LHTs. None of the LHTS had CNS support locally and access to psychology support was via the SGUH psychologist. Overall, they considered that they had good support from the SHT and they were appreciative of the support from the SHT lead clinician since their return from leave in February.

Children and young people living with thalassaemia were seen at either SGUH or ICHT and this pathway was reported as working well.

For young people transitioning to adult care there was limited support in the LHTs and they would value more support for these young people.

Coordination of appointments was reported to be challenging as they were not aware when children and young people were being seen at SGUH and they were often seen at both the SHT and LHT within a short timeframe and therefore better communication would be helpful, including reducing the number of different email communications, so that they could plan and space local follow up appointments. The LHT representatives also commented about spending time chasing results of investigations and not receiving them in a timely fashion.

Those who spoke to the visiting team commented that access to psychometric testing and assessment pathways could be improved and that if the LHTs were able to notify the team directly to refer for support this would be timelier and more beneficial for children and young people in their care.

The also considered that an SHT/LHT development day would be useful, as the WLHCC meetings were often too adult focussed.

SPECIALIST HAEMOGLOBINOPATHY TEAM- CHILDREN AND YOUNG PEOPLE [2]			
St George's University Hospitals NHS Foundation Trust - St George's Hospital	Linked Haemoglobinopathy Coordinating Centres (HCC)		
	West London Sickle Cell HCC *Hosted by Imperial College NHS Trust* The Red Cell Network: Thalassaemia and Rare Inherited Anaemia HCC *Hosted by University College of London Hospitals (UCLH)*		
	Linked Local Haemoglobinopathy Teams LHT	Patient Distribution	
		SCD	Thalassaemia
	Ashford and St Peter's Hospital NHS Foundation Trust	12	0
	Epsom and St Helier's University Hospital NHS Trust	33	0
	Frimley Health NHS Trust - Frimley Park Hospital	12	<=5
	Kingston and Richmond NHS Foundation Trust	14	<=5
	Royal Surrey County Hospital NHS Foundation Trust	<=5	<=5
	Surrey & Sussex Healthcare NHS Trust - East Surrey Hospital	28	6

[2] Note, data have been rounded to the nearest 5 and numbers of 5 or lower suppressed, to ensure that no patient can be identified through publication of small numbers.

PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM							
Condition		Registered patients	Active patients*[3]	Annual Review **	Long term transfusion	% Eligible patients on hydroxycarbamide	Inpatient admissions in the last year
Sickle Cell Disorder	CYP	210	Data not available	Data not available	11	73	Data not available
Thalassaemia and RIA	CYP	35	Data not available	Data not available	5	N/A	Data not available

Staffing

Specialist Haemoglobinopathy Team - Children and Young People	Number of patients	Actual PA or WTE (at the time of the visit)
Consultant haematologist/paediatrician dedicated to work with patients with haemoglobinopathies	245	14PA for all paediatric non-malignant haematology - no cover on Mondays
Clinical Nurse Specialist dedicated to work with paediatric patients living with haemoglobinopathies	245	0.756 WTE 0.24 WTE vacant
Clinical Nurse Specialist dedicated to work with paediatric patients living with haemoglobinopathies in the community	162	2 WTE employed by Central London Community Healthcare NHS Trust. No CNS support for patients cared for by the LHTs in Surrey and Sussex
Clinical Psychologist dedicated to work with paediatric patients living with haemoglobinopathies	245	0.6 (0.4 sickle & 0.2 cognitive assessments)

Urgent and Emergency Care

All children local to SGUH requiring emergency assessment were assessed in the paediatric emergency department by the on call paediatric team and then admitted to the paediatric ward as necessary. There were clinical alerts on children's medical notes to alert teams that they have a haemoglobin disorder and to inform the paediatric SHT service of any admissions.

In-patient Care

Inpatient facilities comprised three paediatric wards (two medical, one surgical). Children were usually admitted to the general paediatric ward, Frederick Hewitt Ward. Federick Hewitt Ward had 17 beds of which five were single rooms. The ward had a school room and adolescent ward area. Adjacent to the ward was a day room for young people.

Any children and young people requiring level 2 or 3 care were admitted to the on-site paediatric intensive care unit

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

Day Care

For haemoglobinopathy patients requiring simple phlebotomy they could attend the paediatric phlebotomy services at Dragon Children's Centre (SGH), St John's Centre (near Clapham Junction) or the Nelson Health Centre (Merton).

Children and young people could attend for their blood transfusions on Jungle Ward, the Surgical and Medical Day Case Unit, Monday to Friday, but not at weekends due to the reduced medical and nursing cover at weekends. There were no side rooms on the unit if children attending for day treatments needed to isolated and in these instances they would have to attend the paediatric emergency department.

Young people over the age of 13 years having red cell exchange transfusions attended the adult apheresis unit on Gordon Smith Ward and the procedure were performed in a side room. The small number of children under the age of 13 years of age, who were already on exchange transfusions prior to the introduction of the minimum age of 13 years had their exchange transfusions performed on Jungle Ward, cared for by a member of the adult apheresis team.

The Blue Sky Ambulatory Unit offered a rapid access outpatient clinic provision and was open from 7:30am to 8pm 7 days a week and located next to Frederick Hewitt Ward. The unit and provided specialist paediatric input for children who required an urgent but not emergency assessment. The unit had four chairs and two consulting rooms.

Outpatients

All outpatient clinic appointments took place in Dragon Centre, Childrens Outpatients and most reviews were attended by the consultant paediatric haematologist and the CNS with some telephone appointments offered for interim reviews. Transcranial doppler scans were usually arranged at the same time as a clinic appointment and took place in the vascular laboratory. There was also a joint respiratory clinic for children with sickle cell disease and respiratory complications.

Community- based care

Community sickle cell services were provided on a borough/ICB basis and currently only available to children living within Wandsworth, Lambeth and Croydon. Wandsworth services were provided by CLCH and there was a weekly MDT with the community team. The community team had previously attended clinics but at the time of the visit this had ceased. Lambeth services were provided by Guys and St Thomas' NHS Foundation Trust (GSTT) and based at the Wooden Spoon Centre. Croydon operated an integrated model for hospital and community sickle cell services and provided community support to children who were resident in the borough. The NHSE commissioned community service pilot with oversight from the South West London (SWL) ICB, once implemented would see the expansion of community sickle cell services to cover Kingston, Richmond, Sutton and Merton. This service would be delivered by CLCH and was due to commence from late March 2025. The CLCH service was based at Tudor Lodge Health Centre, Victoria Drive but also worked from Merton Civic Centre, Falcon Road (Clapham Junction) and Roehampton Lane.

Good Practice

1. A joint clinic between the SHT and the respiratory team was in place which provided a holistic approach to seeing patients living with haemoglobin disorders who also had respiratory conditions. This had enabled patients to be jointly assessed, treatment plans reviewed and a more direct referral to other services for example sleep studies.
2. The CNS and psychology service had found innovative ways of engaging with patients. Some engagements were held virtually so that CYP further away and cared for in the LHTs could join.

3. All children and young people living with SCD, Thalassaemia or RIA who may need to attend the PED had clinical alerts in place on their care records.
4. The TCD service was very flexible and accommodating. Reviewers heard of instances whereby children could have their TCD undertaken at weekends to avoid further school absences.
5. The NHSE Enhanced community care pilot had increased community support for families and children residing in the locality of the South West London ICB.
6. One of the parents had written and published a book A-Z of Sickle Cell disease explaining key aspects of the disease and investigations for younger children. The SHT had been able to gain charitable funding to enable copies of the book to be available for children.

Immediate Risk

1. **Paediatric Specialist Haemoglobinopathy Team (SHT) Consultant Workforce**[4]

   Reviewers were extremely concerned for the clinical safety and clinical outcomes of children and young people with haemoglobin disorders cared for by the trust as there were insufficient consultant staff with specialist experience in the care of children with haemoglobin disorders on site to provide scheduled care, and at the time of the visit, unscheduled care was supported by Imperial College Healthcare NHS Trust (ICHT).

   The SHT had two consultant paediatric haematologists, with some support from a consultant paediatrician with a specialist interest in haematology, who provided speciality care for all non- malignant haematology including the specialist care of approximately 250 children and young people with haemoglobin disorders. Fifty percent of these children and young people received their care from six local haemoglobinopathy teams who required access to specialist care and advice from the SGUH as their SHT.

   At the time of the visit, due to working patterns there was no onsite cover by a consultant paediatric haematologist or consultant paediatrician with a specialist interest in haematology for scheduled or unscheduled care on Mondays. There had not been any haematology trainees rotating through the paediatric service since 2019 and the clinical nurse specialist only worked Tuesday to Thursdays. The consultant paediatrician with a specialist interest in haematology was also about to take a career break for three months.

   The trust had been unsuccessful in appointing to the vacant consultant paediatric haematologist post, and from discussions with trust staff the last time the post was advertised was May 2024 and the reasons for not readvertising since this time were not clear.

   The agreed SLA between Imperial College Healthcare NHS Trust and St George's University Hospitals NHS Foundation Trust (SGUH) to provide temporary 24/7 telephone advice to the Trust had been due to cease at the end of February 2025, however the SLA had been extended until April 2025 on condition that the Trust agreed how to address the service risk.

   The risk to children and young people had been identified and documented on the Trust risk register since 2023 but apart from the interim emergency arrangements with ICHT, as a result of multiple consultant staff absences, the trust had not agreed a strategic plan to address the risk and at the time of the visit were considering a range of options.

[4] See Appendix 3 for the Trust and UKFHD Responses

Serious Concern

1. **Access to Apheresis**

   Reviewers were concerned about the provision of apheresis at the Trust and the pathway for children and young people to access an elective automated red cell exchange programme (aRCE)

   At the time of the visit only young people over the age of 13 years were now accepted to receive aRCE at the Trust although there was an established adult service. Reviewers were told that they had been an all age service but this had now ceased except for the children who had already been accepted on the programme at the Trust. This had resulted in children under the age of 13 years, who needed to start an exchange transfusion programme being referred to another centre. There was no established aRCE pathway and it occurred on a case by case basis with children attending either St Mary's Hospital (ICHT) or Evelina London Children's Hospital.

Concern

1. **Clinical Nurse Specialist Workforce**

   The reviewers were concerned that the service had insufficient CNS staffing for the number of children under the care of SHT for the following reasons

   a. At the time of the visit there was only 0.76 WTE available on 3 days a week and there was no cover for absences. Some emergency cover was in place from the Paediatric Haemophilia Clinical Nurse Specialist but this was limited to signposting and not for emergency cover or scheduled activities.

   b. Due to the CNS working schedule the lead nurse did not have appropriate time for leadership and was unable to attend the HCC nurse network meetings.

   c. The increase in the number of children and young people with haemoglobin disorders was having an impact on the capacity of the CNS being able to support children and young people receiving shared care with the LHTs. The CNS was also covering new born screening which included discussing the results and providing early support for families.

   d. The SHT did have an 0.24 (9hrs) vacancy but had not been able to recruit to the limited hours available.

2. **Access to Psychology**

   Access to psychology was insufficient to meet the needs of the 245 children and their families cared for by the SHT. There was only 0.6 WTE time available consisting of 0.4 WTE for children and their families living with a haemoglobin disorders and 0.2WTE allocated for cognitive assessments which did not meet the British Psychological Society Special Interest Groups in Sickle Cell and Thalassaemia (2017) recommendation of 1 WTE HCPC Senior Psychologist for every 300 patients.

3. **Training and Competence Framework**

   Due to the shortages in workforce across the SHT, they had limited time to provide training to ED and nursing staff on wards and areas to which children and young people were usually attended or were admitted. Some ED staff and ward nurses had received training in haemoglobinopathies, but a formal competence framework and process for assessing knowledge and ongoing monitoring was not yet in place. Nursing staff did have competences in transfusion, venepuncture and cannulation.

4. **Data and administrative support.**

   The SHT had only 1 WTE secretary shared between haematology, oncology & cardiology and the secretary was leaving at the end of March 2025 and consultant and nursing staff were spending clinical time on administrative tasks, including arranging future blood test appointments when patients attended clinics. At

the time of the visit here was no support for data collection, audits or data for NHR. Reviewers were told that there was funding for a 0.4WTE data support role, but at the time of the visit recruitment to this post had not commenced.

5. **Patients living with Thalassaemia**

   Much of the guidance and information was related to those living with a Sickle Cell Disorder and not for those living with Thalassaemia. Reviewers were concerned that, although the SHT had a low number of patients living with Thalassaemia under their care, this could lead to inequity of provision and as such poorer patient outcomes.

6. **Transition**

   The pathway for young people transitioning to adult care was of concern for the following reasons:-

   a. A robust process for starting early preparation transition was not in place. There was no agreed starting point for the 'ready' stage of transition. There was inconsistency with when and for whom it was started. There was also no dedicated lead for transition which led to lack of ownership for this part of the service. Reviewers did not see any evidence of any transition documentation that could be individualised for the young person.

   b. The transition clinic was held on a Friday, on the day that the Paediatric CNS did not work therefore it was not possible to provide a joint MDT approach to transition. This had resulted in ad hoc joint clinics taking place.

   c. There did not appear to be named leads for each of the MDT elements across both the adult and paediatric services which proved difficult in identifying who would have responsibility and the expertise to ensure young people were supported at the various times of their transition.

   d. At the time of the visit, all patients aged 16 and 17year of age at the SHT site were managed by the paediatric team for outpatient, ED and inpatient care and were not seen by adult teams until 18 years of age. The potential exception to this would be the new Pan South Thames Intensive Care pathway whereby 16 and 17 year olds and those whose weight was greater than 50kg would be admitted to an adult rather paediatric intensive care unit, even if not transitioned to adult service.

   e. There was limited targeted written information on transition available at an age-appropriate level.

   f. For young people transitioning to adult care there was limited support in the LHTs and representatives who spoke to the reviewing team commented that they would value more support for these young people.

Further Consideration

1. The SHT did not have any service level agreements with community services based in the local boroughs who were providing care to children and families living with a haemoglobin disorder. Agreeing SLAs with these community services would clarify responsibilities, improve collaboration and reduce overlapping of work.

2. Jungle Ward Unit was open at weekends to care for patients undergoing surgery and reviewers considered that there may be opportunities to offer children and young people the option to attend for their transfusions at weekends, especially at times when young people were studying for exams.

3. The SHT did not have any shared care agreements with their constituent LHTs. Reviewers considered that formalising responsibilities with the LHTs would provide clarity around shared care arrangements and coordination of transition to adult services for young people.

Specialist Haemoglobinopathy Team (Adult Services)

General Comments and Achievements

The Red Cell and Haemoglobin Disorders Unit sat within the Haematology Care Group and was supported by the operational management team, including the Haemoglobinopathies Pathway Manager and Data Manager. There had been recent investment in the service with increased staffing achieved across medical, nursing, administrative, and community support. Hot clinics for patients living with a sickle cell disorder had commenced in January 2025, the opening hours of the Apheresis Unit had been recently extended and the opening of a Hyper Acute Unit (HAU) with two year NHS England funding was imminent.

The team were a positive forward-thinking service that worked around finding solutions to challenges and had worked hard to design new roles. The service was actively supported by the senior management team.

At the time of the review, the SGUH SHT had 459 adult patients with haemoglobin disorders registered with around 25% of these under the shared care of an LHT. The services provided at SGUH included:

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

The Adult Service was a consultant led multidisciplinary team. The service employed three consultants (one locum in place with an advert out for a substantive post). The team were also supported by a further locum consultant on an attending rota.

Consultants attended the haemoglobinopathy MDT, were part of haemoglobinopathy clinics; the red cell attending rota and the non-malignant on call rota. The service was further supported by a team of resident doctors who for training, rotated through the red cell service, worked supernumerary in haemoglobinopathy clinic for training, were invited to attend MDTs and were supported by a 24/7 non-resident on-call consultant.

There was one WTE Lead Nurse for Haemoglobinopathies who was due to commence in post in April 2025 and would work with the 1.8 WTE clinical nurse specialists who were in post. A 0.2 WTE pharmacist was also due to commence in July 2025 to support the Hyper Acute Unit (HAU) and clinics.

Psychology Service

The Red Cell Pain Management and Psychology Service (RCPMPS) was provided by a one WTE Clinical Psychologist and Service Lead, one WTE clinical psychologist, and a 0.6 WTE Assistant Psychologist.

The RCPMPS psychology service at St George's Hospital provided specialist care to patients in both inpatient and outpatient settings who received their care at St George's hospital and partner hospitals in the region, and for patients living in Wandsworth, Merton, Sutton, Kingston, and Richmond. The service also offered expert outpatient pain management input nationally.

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

Joint pain self-management assessments with a Clinical Psychologist and Physiotherapist were offered as part of a multidisciplinary approach to pain management. RCPMPS actively contributed to weekly multidisciplinary team (MDT) meetings, discuss governance-related issues, and attend regular care group meetings.

Cross Specialty Relationships

SGUH provided a maternal medicine centre for obstetric care (MMC). Sickle Cell Disease and Transfusion Dependent Thalassaemia was classed as category C conditions where care in pregnancy was led by the MMC. All pregnant women living with a sickle cell disorder or thalassaemia had a named midwife and had MDT support from foetal medicine, maternal medicine, obstetric physicians, obstetric anaesthetics, midwives and haematology. The SHT provided teaching to the obstetric team and had also presented at the Southwest London and Surrey Heartlands Maternal Medicine Network 'Haematology in Obstetrics' day in February 2025.

There were close working relationships with other specialities including the complex arthroplasty unit, neurology, renal, urology, cardiology, and critical care.

Transition

Transition was based on the national Ready Steady Go Hello framework. Young people were asked to complete a questionnaire and view videos about transition and once approaching their 18th birthday, a meeting was arranged for the patient to meet with the adult clinical team to commence the transfer process with a tour of the adult facilities provided.

For young people studying away from home a referral was made to the LHT nearest to their university and information was provided to the young person. The CNS was the named coordinator and would follow up one month after the young person had transitioned to adult care including any clinic non-attendance.

SPECIALIST HAEMOGLOBINOPATHY TEAM- ADULT [5]			
St George's University Hospitals NHS Foundation Trust - St George's Hospital	Linked Haemoglobinopathy Coordinating Centres (HCC)		
	West London Sickle Cell HCC Hosted by Imperial College NHS Trust The Red Cell Network: Thalassaemia and Rare Inherited Anaemia HCC Hosted by University College of London Hospitals (UCLH)		
	Linked Local Haemoglobinopathy Teams LHT	Patient Distribution	
		SCD	Thalassaemia
	Ashford and St Peter's Hospital NHS Foundation Trust	20 (18 under SHTs) (2 not on NHR)	<=5
	Epsom and St Helier's University Hospital NHS Trust	48 (45 under SHT) 13 not on NHR	8 not on NHR
	Frimley Health NHS Trust - Frimley Park Hospital	11	<=5
	Kingston and Richmond NHS Foundation Trust	0	5 (3 under SHTs) (2 not on NHR)
	Royal Surrey County Hospital NHS Foundation Trust	10	<=5
	Surrey & Sussex Healthcare NHS Trust - East Surrey Hospital	37 (36 under SHTs, 1 on NHR with No SHT)	4 (4 under SHTs: 3 Thalassaemia and 1 RIA) (13 not on NHR, all are RIA)

[5] Note, data have been rounded to the nearest 5 and numbers of 5 or lower suppressed, to ensure that no patient can be identified through publication of small numbers.

PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM							
Condition		Registered patients	Active patients*[6]	Annual Review **	Long term transfusion	% Eligible patients on hydroxycarbamide	Inpatient admissions in the last year
Sickle Cell Disorder	Adults	405	383	No annual reviews undertaken	160	69	193
Thalassaemia and RIA	Adults	54	54	No annual reviews undertaken	20	0	<=5

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual PA or WTE (at the time of the visit)
Consultant haematologist dedicated to work with patients with haemoglobinopathies	459	3 WTE plus attending locum
Clinical Nurse Specialist dedicated to work with patients living with haemoglobinopathies	459	1.8 WTE CMS plus 1.0 WTE lead nurse to start April 25.
Clinical Nurse Specialist dedicated to work with patients living with haemoglobinopathies in the community	459	3 WTE employed by CLCH
Clinical Psychologist dedicated to work with patients living with haemoglobinopathies	459	2 WTE

Urgent and Emergency Care

Patients presenting with acute complications were admitted through the Emergency Department (ED) where the ED clinicians liaised with the on-call haematology team for assessment and initiation of care following available guidelines and individual universal care plans. There was a 24/7 haematology registrar on call and a 24/7 haematology consultant on call rota. When the consultant on call was a specialist in malignant haematology a second on call non-malignant haematology consultant was available.

There was a named link consultant and link nurse in the ED alongside close working with the practice educator and regular teaching sessions.

Patients requiring admission were transferred to one of the designated haematology wards for specialised care. Patients could also be transferred from local hospitals for specialist and critical care if required.

SGUH was participating in the NHS England Emergency Department Bypass pilot for patients with SCD. From spring of 2025 the HAU was aiming to open, allowing patients with sickle cell disease suffering from a painful vaso-occlusive crisis to bypass ED. Plans for this process involved:

- Access to a 24/7 phone line to advise on admission pathway staffed by trained nurses.
- Access to a dedicated bed on a haematology ward for urgent review avoiding the emergency department.
- Access to a hot clinic available Monday-Friday to avoid either attendance to the emergency department, to avoid admission at all or to enable early discharge.

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

In-patient Care

Patients requiring admission transferred to the designated haematology wards (Gordon-Smith Ward, Trevor Howell Ward or Ruth Myles Ward) for specialised care. The wards were light, colourful and information covering Sickle Cell Disorders was visible and accessible.

The Gordon Smith and Trevor Howell Wards were both haematology and oncology wards and collectively provided 31 beds including five side rooms. The Ruth Myles Ward was a haematology and transplant ward with 12 single rooms. Once open the Hyper Acute Unit would be located on the Gordon Smith Ward.

Pain medication was delivered via sub-cutaneous bolus rather than patient-controlled analgesia (PCA) that the nurses on the ward reported worked well. Rarely if a patient required PCA they could be transferred to a surgical or medical ward.

On the day of the visit all the haemoglobinopathy patients were on the Gordon Smith Ward, staff reported that when this ward was full, the other two dedicated wards were used.

Day Care

The Ruth Myles Day Unit was co-located within the Ruth Myles Ward. The unit was open between the hours 9am to 5pm Monday to Friday, the unit accommodated three chairs for patients receiving top up transfusions, specialised phlebotomy and space to provide patient clinical reviews. All the staff who were band 5 and above had cannulation and transfusion competencies as evidenced on the day in dedicated training folders.

The Apheresis Unit was co-located with the Gordon-Smith Ward which comprised of four beds. One of these was a side room which was used for the young people over the age of 13 years. For automated red cell exchange and plasmapheresis (as well as leukodepletion and stem cell collection) the service was available as outpatient elective service six days a week and an emergency service seven days a week 8am-8pm. The number of patients receiving red cell exchange transfusion had doubled over to last 5 years to 1025 transfusions in 2024/25. 166 patients were on the elective automated red cell exchange programme (including patients from Croydon University Hospital, who were referred for aRCE due to geographical preferences rather than attend other central London services).

The review team heard from staff that they had consistently received good feedback from patients. Most patients were exchanged via peripheral access, many using single arm access. The unit also contributed to teaching and training of other staff and other units.

Outpatients

Haematology and Oncology Outpatients (HOOP) was the base for nursing, psychology and medical haemoglobinopathy clinics. Six hours a week from a ‘Full Circle’ community grant funded complementary therapy inpatient and outpatient sessions for patients living with SCD provided remedial massages and reiki as part of the wider holistic care available to patients.

At the Phoenix Centre there was a dedicated light and pleasant group room for psychology use, both for group work and for individual sessions.

Community- based care

Community Services for Sickle Cell & Thalassaemia were provided by three WTE clinical nurse specialists employed by Central London Community Health NHS Trust (CLCH) for the boroughs of Wandsworth, Merton, Kingston, Richmond and Sutton.

The community nursing team had good lines of communication with the patients and hospital team and participated in a weekly MDT.

Views of Service Users and Carers

During the visit the review team met with two adults living with a sickle cell disorder and one adult living with thalassaemia.

Service User Feedback

Patients living with a Sickle Cell Disorder

- They commented that they were able to contact the Clinical Nurse Specialist who would soon contact them
- It was reported that they tried to avoid the ED at their local hospital as they had to wait too long for pain relief and they were not sure who they were liaising with at SGUH about their care. They described how they would try and self-manage for 48 hours before attending the ED.
- Their GP's were good and listened, understood the importance of their support and were knowledgeable.
- As an LHT patient they had not received any information about SGUH support services and were unable to access them because of where they lived.
- Those who accessed the apheresis service were highly complementary about the care they received. It was commented that they used to have a femoral line, but they now had access via the arm.
- A SGUH, a patient had attended the Emergency Department last May, they received one painkiller and were not reviewed. They described that they had been able to phone the CNS who arranged transfer to the ward, but in future would avoid attending the Emergency Department.
- There was good psychological support from the team.
- If they could change anything it would be increased input into the Emergency Department.

Patient living with Thalassaemia

- The patient was happy with the care received. The pathway was smooth, as were the booking of appointments.
- They sometimes had difficulty accessing medication from pharmacy.
- With regards to phlebotomy, prior to the electronic system the paper forms used to have red dot so the haemoglobinopathy patients had priority over less regular attendees. The electronic system did not support this, so they now had to queue.
- The patient had no awareness of patient relevant information from the trust but used the UKTS information.
- They were happy with the care they received from the clinical team and the response from the CNS was timely and supportive when needed.

Good Practice

1. There was an excellent Psychology Service. A psychologist attended the ward round which helped to establish psychology support as the norm for patients rather than something unusual.
2. They worked with GPs to support with opiate prescriptions and care planning and offered both group and individual therapy sessions for patients living with red blood cell conditions. In addition to individual support, the team ran a monthly online support group to provide a safe and accessible space where patients with sickle cell and thalassaemia could share experiences and connect with others.
3. There was an excellent specialist pain management clinic in operation, co-led by a Consultant in Pain Management and a Clinical Psychologist. Joint self-management assessments with a clinical psychologist and physiotherapist were offered as a multidisciplinary approach to pain management.

4. The review team were really impressed that LHTs had engaged with the time to analgesia audit and were able to actively speak about this. The LHTs representative who spoke to the review team were spoke highly of the support they received by the SHT.
5. There was a good nurse competency framework in place on the Apheresis Unit and for nursing staff on the wards with clear evidence of the level of training provided and completion of competences. The practice nurse educator had a good oversight of training needs, and the review team commended her commitment and dedication.
6. QR codes were in use and visible on the ward to provide patients and staff with up to date information on the soon to be opening HAU.
7. The Apheresis Unit practice was noted particularly with regards to the use of the single arm access supported by ultrasound cannulation. This enabled patients to use their other arm during the procedure which significantly enhanced their experience.
8. Full Circle, who provided complimentary therapies, had funded complementary therapies which were available to inpatients and outpatients including reiki, massage, and mindfulness. This was a highly valued service by both staff and patients.
9. A Social Prescribing and Health and Well-being coach (0.6 WTE) had been in post since January 2025. The coach worked with patients to help connect them to community resources such as well-being programmes, lifestyle services, and employment support, to enhance quality of life outside of clinical settings.
10. The SHT held dedicated thalassaemia clinics three times a year. Reviewers were impressed as the SHT did not have a large population of patients with thalassaemia and rarer inherited anaemias and the dedicated clinics would allow more focus on the specific care needs for this patient cohort.
11. The review team observed clear and meaningful engagement from trust senior management who collaborated closely with clinical teams to understand any risk, develop business cases, and identify funding in response to patient need.
12. The Clinical Nurse Specialists felt supported by nurse leaders and described clear development pathways such as nurse prescribing and advanced competencies.

Immediate Risk

No immediate risks were identified during the course of the visit.

Serious Concerns

No serious concerns were identified during the course of the visit.

Concern

1. **Transition**

   The pathway for young people transitioning to adult care was of concern for the following reasons:-

   a. A robust process for starting early preparation transition was not in place. There was no agreed starting point for the 'ready' stage of transition. There was inconsistency with when and for who it was started. There was also no dedicated lead for transition which led to lack of ownership for this part of the service. Reviewers did not see any evidence of any transition documentation that could be individualised for the young person.

   b. The transition clinic was held on a Friday, on the day that the Paediatric CNS did not work therefore it was not possible to provide a joint MDT approach to transition. This had resulted in ad hoc joint clinics taking place.

c. There did not appear to be named leads for each of the MDT elements across both the adult and paediatric services which proved difficult in identifying who would have responsibility and the expertise to ensure young people were supported at the various times of their transition.

d. At the time of the visit, all patients aged 16 and 17year of age at the SHT site were managed by the paediatric team for outpatient, ED and inpatient care and were not seen by adult teams until 18 years of age. The potential exception to this would be the new pan-South Thames Intensive Care pathway whereby 16 and 17 year olds and those whose weight was greater than 50kg would be admitted to an adult rather paediatric intensive care unit, even if not transitioned to the adult service.

e. There was limited targeted written information on transition available at an age-appropriate level.

f. For young people transitioning to adult care there was limited support in the LHTs and representatives who spoke to the reviewing team commented that they would value more support for these young people.

2. **Lead Nurse Funding**

   A lead nurse had been appointed to commence in post from April 2025 however this was an 18-month fixed term contract. The review team were concerned that with the growing service this post needed to be sustainable. Reviewers however were reassured that from discussions during the visit the General Manager was aware of the risk and was working to establish the post in the long term.

3. **Frimley Park Local Haemoglobinopathy Team**

   The review team were concerned about the pathway for patients being cared for at the LHT at Frimley Park Hospital. Reviewers heard some concerning patient experience, and there was no representation from the LHT on the day of the peer review visit.

   There was no shared care agreement in place to clarify the roles and responsibilities between the SGUH SHT and Frimley Park LHT. The review team acknowledged that Frimley Park also had links with the SHTs based in Oxford, and Kings College as well as St George's, which complicated the pathway and were concerned that greater assurance on the care these patients and any support the LHT required should be prioritised.

4. **Support for Adult LHT – Crawley**

   The LHT based in Crawley (Surrey and Sussex Healthcare NHS Trust) did not have any CNS support for what was a relatively large patient cohort. Whilst this was not the direct responsibility of SGUH SHT to resolve, the SHT and Network should try and advocate regarding this and exert some influence over the LHTs management and consider flagging to commissioners.

Further Consideration

1. The review team heard that the LHTs would like access to London Care Records as they have patients presenting from these hospitals into their EDs. There was a link into the universal care management system available that LHTs could be provided with and access explored. The review team also highlighted the availability of Universal Care Plans which would provide visibility of pain plans of any patients living with a Sickle Cell Disorder.

2. Consideration should be given to expanding research for the medical team but also as a priority for the wider MDT. The review team felt that as an organisation there was a good nursing research portfolio that the service could link with to provide support and opportunity. The MDT were doing magnificent work which could be presented at conferences for wider team development and exposure.

3. The review team heard that the Apheresis service was on the risk register in terms of the growing demand and the need to increase the capacity including the size of the estate available. The senior leadership were aware of the need to future proof the service and were considering options and capital funding to support.
4. The review team heard that the lack of CNS support at some LHTs was creating inequity to patient care. The lead nurse commencing in April 2025 should consider what support she may be able to provide to LHTs direct, or support for LTHs to achieve dedicated resource.
5. The service should consider how they could increase patient involvement in the SHT service organisation. The review team noted a good example with the patient inclusion in the development of the HAU and felt they should expand on this. It was recommended that the use of the psychology support groups was an opportunity.
6. There were good written information leaflets, but the patients reported they were unaware of them. Consideration should be given to improving patient awareness and access.
7. There was no dedicated dietician for haematology patients with support provided by the infectious diseases dietician or other ward allocated dieticians, which the review team heard were at maximum capacity. Consideration should be given to securing dedicated dietetics resource.
8. The community nursing team described an opportunity to further improve the patient pathway through the development of a systematic approach to discharge.
9. The electronic system for phlebotomy could not support prioritisation so patients living with haemoglobin disorders, attending on a regular basis, had to wait in the queue. Previously they had been able to be prioritised and consideration should be given as to how this could be re enabled.

Commissioning

The review team had discussions with commissioner representatives from NHS England London, NHS South West London ICB, and South London Office of Specialised Services. Several issues in this report will require the active involvement of the Trust leadership team and commissioners to ensure timely progress is made.

Concern

1. Projects such as the adult psychology resource, complimentary therapy, and social prescribing were funded by NHSE as part of the Sickle Cell and Thalassaemia Community Project which was provided on a two-year pilot. Although there was ICB commitment to continue, the review team were concerned that the political climate specifically around shifting ICB and NHSE finances may disrupt such highly valued services.

Appendix 1 Membership of Visiting Team

Visiting Team		
Ryan Mullally	Consultant Haematologist	Whittington Health NHS Trust
Matty Asante-Osuwu	Community Sickle Cell Matron	Whittington Health NHS Trust
Deo Boodoo	Lead Nurse for Sickle Cell and Thalassaemia	Barking, Havering and Redbridge NHS Trust
Emma Astwood	Consultant Paediatric Haematologist	Sheffield Children's NHS Trust
Natasha Lee	Paediatric Sickle Cell and Thalassaemia Nurse Specialist.	Barking, Havering and Redbridge NHS Trust
Lesley McCarthy	Haematology Nurse Specialist	Oxford University Hospitals NHS Trust
Cherryl Westfield	User Representative	

Clinical Leads		
Rachel Kasse-Adu	Consultant Haematologist	Guy's and St Thomas NHS Trust
Sabiha Kauser	Consultant Paediatric Haematologist	Manchester University Hospitals NHS Trust

NHS Midlands and Lancashire		
Kelly Bishop	Assistant Director of Nursing and Urgent Care	NHS Midlands and Lancashire
Sarah Broomhead	Professional Lead	NHS Midlands and Lancashire

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Appendix 2 – Compliance with the Quality Standards

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

Percentage of Quality Standards met

Service	Number of Applicable QS	Number of QS met	% Met
Specialist Haemoglobinopathy Team (SHT) Children and Young People	49	14	29%
Specialist Haemoglobinopathy Team (SHT) Adult	45	34	76%

Quality Standards – Care of Children and Young People

Ref	Standard	Met Y/N	Reviewer comment
HC-101	**Haemoglobin Disorder Service Information** Written information should be offered to children, young people and their families, and should be easily available within patient areas, covering at least: a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Contact interpreter and advocacy services, Patient Advice and Liaison Service (PALS), spiritual support and Healthwatch (or equivalent) v. Give feedback on the service, including how to make a complaint *vi.* Get involved in improving services (QS HC-199)	N	There was no information seen for those living with thalassaemia. Information was not clear for 'b' and 'c' apart from the information that covered admission for minor injuries to Jungle Ward. Information covering 'g' was not specific about where to go in an emergency but did cover when to "seek help" and "seek medical help". 'd' was met but reviewers considered would benefit from review in terms of the language used to differentiate between professions. 'f' information was available covering national haemoglobinopathy support groups and community local health and wellbeing groups. Information did not cover any local haemoglobinopathy support groups. 'h' was met and children were issued with an information passport. There was a very good leaflet about interpreter and advocacy services and how to give feedback. Families could book their phlebotomy appts online.

Ref	Standard	Met Y/N	Reviewer comment
HC-102	**Information about Haemoglobin Disorders** Children, young people and their families should be offered written information, or written guidance on where to access information, covering at least: a. A description of their condition (SCD or Th), how it might affect them and treatment available b. Inheritance of the condition and implications for fertility c. Problems, symptoms and signs for which emergency advice should be sought d. How to manage pain at home (SCD only) e. Transfusion and iron chelation f. Possible complications g. Health promotion, including: i. Travel advice ii. Vaccination advice h. National Haemoglobinopathy Registry, its purpose and benefits i. Parental or self-administration of medications and infusions.	N	Reviewers did not see any information covering 'e, 'f' 'g ii', 'h' and 'I'. Some of the information would benefit from review to be more specific, for example information about causes of a temperature and why they experience pain. Some information seen would benefit from proof reading and had errors especially the pain chart. The SHT had a very good clear age appropriate booklet for older children (7+). A parent had also written and published a book for younger children.
HC-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Planned acute and long-term management of their condition, including medication iii. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed The care plan and details of any changes should be copied to the patient's GP and their local team consultant (if applicable).	Y	Care plans were also accessible on the Trust SharePoint platform.

Ref	Standard	Met Y/N	Reviewer comment
HC-104	**What to Do in an Emergency?** All children and young people should be offered information about what to do in an emergency covering at least: a. Where to go in an emergency b. Pain relief and usual baseline oxygen level, if abnormal (SCD only)	N	The information was very brief and seemed to cover care at home rather than who to contact in an emergency. Some information for 'b' was covered in the information passport.
HC-105	**Information for Primary Health Care Team** Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD) b. Side effects of medication, including chelator agents [SCD and Th] c. Guidance for GPs on: i. Immunisations ii. Contraception and sexual health (if appropriate) d. What to do in an emergency e. Indications and arrangements for seeking advice from the specialist service	N	Information for GPs did not cover 'b' ,'cii', 'd' or 'e'
HC-106	**Information about Transcranial Doppler Ultrasound** Written information should be offered to children, young people and their families covering: a. Reason for the scan and information about the procedure b. Details of where and when the scan will take place and how to change an appointment c. Any side effects d. Informing staff if the child is unwell or has been unwell in the last week e. How, when and by whom results will be communicated	N	The SHT had a good informative booklet although 'd' was not included

Ref	Standard	Met Y/N	Reviewer comment
HC-107	**School or College Care Plan** A School or College Care Plan should be agreed for each child or young person covering at least: a. School or college attended b. Medication, including arrangements for giving/supervising medication by school or college staff c. What to do in an emergency whilst in school or college d. Arrangements for liaison with the school or college e. Specific health or education need (if any)	Y	The school care plans were in a template form and were very detailed with separate templates covering those living with SCD, Thalassaemia and RIAs. The CNS and Psychology team had also provided a range of virtual training sessions for local schools. To encourage attendance families were sent texts to remind them to inform their child's teacher and emails were sent to schools. Those participating would also receive a Q&A handout after the session.
HC-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child-friendly environment, including age-appropriate toys, reading materials and multimedia. There should be sound and visual separation from adult patients.	N	Jungle Ward did not have any single rooms so patients who needed to be isolated could not be accommodated for treatments and transfusions and would have to receive their treatments in the PED.
HC-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care f. Advice for young people leaving home or studying away from home including: i. Registering with a GP ii. How to access emergency and routine care iii. How to access support from their specialist service *iv.* Communication with their new GP	Y	

Ref	Standard	Met Y/N	Reviewer comment
HC-197	**Gathering Views of Children, Young People and their Families** The service should gather the views of children, young people and their families at least every three years using: a. 'Children's Survey for Children with Sickle Cell' and 'Parents Survey for Parents with Sickle Cell Disorder' b. UKTS Survey for Parents of Children with Thalassaemia	N	Surveys had been undertaken in Autumn 2024. However, the Sickle Cell Survey did not meet the QS as there had been < 10% response rate (13/ 210 pts) and no responses had been received for the Thalassaemia and RIA survey. The responses that had been received had been analysed. A psychology service survey for those living with sickle cell disorder had been completed and the 45 responses had been analysed.
HC-199	**Involving Children, Young People and Families** The service's involvement of children, young people and their families should include: a. Mechanisms for receiving feedback b. Mechanisms for involving children, young people and their families in: i. Decisions about the organisation of the service ii. Discussion of patient experience and clinical outcomes (QS HC-797) c. Examples of changes made as a result of feedback and involvement	Y	
HC-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session(s) identified for the role within their job plan and cover for absences should be available.	N	The designated lead had six PAs for all non-malignant haematology and time was not defined for SHT leadership. The lead did not have a job plan. Cover for the lead consultant was from other paediatric consultants.

Ref	Standard	Met Y/N	Reviewer comment
HC-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. Competences in caring for children and young people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	N	The SHT had only 0.76 WTE CNS time for the care of 245 patients. The CNS worked Tuesday to Thursday with no cover on Mondays and Fridays or for annual leave. Some emergency cover was in place from the Paediatric Haemophilia Clinical Nurse Specialist but not for scheduled activities. Due to the CNS working schedule the lead nurse did not have appropriate time for leadership and was unable to attend the HCC nurse network meetings.
HC-204	**Medical Staffing and Competences: Clinics and Regular Reviews** The service should have sufficient medical staff with appropriate competences in the care of children and young people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	Two consultant paediatric haematologists had a total of 14 PAs with an additional Consultant with 0.6 PAs. The time available for hemoglobinopathy work was not defined. None of the consultants had any allocated CPD time for haemoglobinopathies. The Trust had a vacant 1 WTE consultant paediatric haematologist post.
HC-205	**Medical Staffing and Competences: Unscheduled Care** 24/7 consultant and junior staffing for unscheduled care should be available. SHTs and HCCs only: A consultant specialising in the care of children and young people with haemoglobin disorders should be on call and available to see patients during normal working hours. Cover for absences should be available.	N	A consultant specialising in the care of children and young people with haemoglobin disorders was not available on Mondays. Inpatients were reviewed by the SGUH paediatric haematology consultants when available (currently 1.4WTE) and due to staffing shortages this was not always possible. Arrangements had been in place to provide advice from another SHT. *See Immediate risk section of the main report.*

Ref	Standard	Met Y/N	Reviewer comment
HC-206	**Doctors in Training** If doctors in training are part of achieving QSs HC-204 or HC-205 then they should have the opportunity to gain competences in all aspects of the care of children and young people with haemoglobin disorders.	N/A	The SHT had not had any doctors in training allocated to them since the Covid-19 pandemic.
HC-207	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of children and young people with haemoglobin disorders, including: a. Clinical nurse specialist(s) with responsibility for the acute service b. Clinical nurse specialist(s) with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	There was insufficient CNS time (0.76WTE band 7) for the care of 245 patients and no cover for absences except in an emergency from the haemophilia CNS. There was 0.24WTE CNS vacant post. Nurses on the wards had not completed any competences in the care of the care of patients living with haemoglobin disorders. Competences covering cannulation, venepuncture and blood transfusion had been completed. Community support was provided by Central London Community Healthcare NHS Trust.
HC-208	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of children and young people with haemoglobin disorders, including: a. An appropriate number of regular clinical session(s) for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multidisciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuropsychology Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	The SHT only had 0.6 WTE psychology time for 245 patients (0.4WTE for haemoglobinopathies and 0.2 WTE to undertake cognitive assessments) and to provide support to patients based at the LHTs.

Ref	Standard	Met Y/N	Reviewer comment
HC-209	**Transcranial Doppler Ultrasound Competences** Sufficient staff with appropriate competences for Transcranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	Y	
HC-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	N	The SHT had only one WTE secretary shared between haematology, oncology & cardiology and the secretary was leaving at the end of the month. There was no support for data collection, audits or data for NHR although reviewers were told that there was funding for a 0.4WTE data support role.
HC-301	**Support Services** Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HC-602) as required: a. Social worker/benefits adviser b. Play specialist/youth worker c. Dietetics d. Physiotherapy (inpatient and community-based) e. Occupational therapy f. Child and adolescent mental health services	Y	Access to benefits advisor was via Roald Dahl Marvellous Children's Foundation. A care navigator would be accessible to families as part of the SW London community project. All other support services were available locally.
HC-302	**Specialist Support** Access to the following specialist staff and services should be easily available: a. DNA studies b. Genetic counselling c. Sleep studies d. Diagnostic radiology e. Manual exchange transfusion (24/7) f. Automated red cell exchange transfusion (24/7) g. Pain team including specialist monitoring of patients with complex analgesia needs h. Level 2 and 3 critical care	N	Automated red cell exchange was only available for young people aged 13 and above. *See main report.*

Ref	Standard	Met Y/N	Reviewer comment
HC-303	**Laboratory Services** UKAS/CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y	South West London Pathology
HC-304	**Urgent Care – Staff Competences** Medical and nursing staff working in the Emergency Departments and admission units should have competences in urgent care of children and young people with haemoglobin disorders.	N	Training was provided on an ad hoc basis and when capacity allowed. There was no process for assessment of competences for staff in the ED.
HC-501	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their family or carer, paediatric and adult services, primary health care and social care in planning the transfer, including a joint meeting to plan the transfer of care c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between HCCs, SHTs and LHTs (if applicable) h. Responsibilities for giving information to the young person and their family or carer (QS HC-195)	N	Transition guidelines were in place but had not been fully implemented ('f 'g' and 'h').
HC-502	**New Patient and Annual Review Guidelines** Guidelines or templates should be in use covering: a. First outpatient appointment b. Annual review Guidelines should cover both clinical practice and information for children, young people and their families.	N	The TIF Guidelines for the Management of Transfusion-Dependent Thalassaemia were in use but there was no localised information to accompany the guidance. This QS was met for SCD.

Ref	Standard	Met Y/N	Reviewer comment
HC-504	**Transcranial Doppler Ultrasound Standard Operating Procedure** A Standard Operating Procedure for Transcranial Doppler ultrasound should be in use covering at least: a. Transcranial Doppler modality used b. Identification of ultrasound equipment and maintenance arrangements c. Identification of staff performing Transcranial Doppler ultrasound (QS HC-209) d. Arrangements for ensuring staff performing Transcranial Doppler ultrasound have and maintain competences for this procedure, including action to be taken if a member of staff performs less than 40 scans per year e. Arrangements for recording and storing images and ensuring availability of images for subsequent review f. Reporting format g. Arrangements for documentation and communication of results h. Internal systems to assure quality, accuracy and verification of results	Y	

Ref	Standard	Met Y/N	Reviewer comment
HC-505	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: I. Emergency and regular transfusion II. Use of simple or exchange transfusion III. Offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for: I. Manual exchange transfusion II. Automated exchange transfusion on site or organised by another provider c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts e. Arrangements for accessing staff with cannulation competences f. Patient pathway and expected timescales for regular transfusions, including availability of out of hours services (where appropriate) and expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion g. Patient pathway for Central Venous Access Device insertion, management and removal	N	Transfusion guidance did not cover those living with thalassaemia. WLHCC SCD guidelines did meet the requirements of the QS but could not implemented at SGUH as Apheresis was not available for children under the age of 13 and there was no protocol to follow should a child require referral to another aRCE service.
HC-506	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug(s), dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible	N	The guidance did not cover Thalassaemia or the process to access T2* elsewhere. Guidance was seen covering those with SCD.

Ref	Standard	Met Y/N	Reviewer comment
HC-507	**Hydroxycarbamide and Other Disease Modifying Therapies** Guidelines on hydroxycarbamide and other disease modifying therapies should be in use covering: a. Indications for initiation b. Monitoring of compliance and clinical response, including achieving maximum tolerated dose for hydroxycarbamide c. Documenting reasons for non-compliance d. Monitoring complications Indications for discontinuation	Y	WL HCC Sickle Cell Guidance
HC-508	**Non-Transfusion Dependent Thalassaemia (nTDT)** Guidelines on the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy d. Consideration of options for disease modifying therapy	N	There was no guidance covering nTDT. In practice the team followed the TIF guidance.

Ref	Standard	Met Y/N	Reviewer comment
HC-509	**Clinical Guidelines: Acute Complications** Guidelines on the management of the acute complications listed below should be in use covering at least: I. Local management II. Indications for seeking advice from the HCC/SHT III. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred For children and young people with sickle cell disorder: a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision k. Acute splenic sequestration For children and young people with thalassaemia: l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation	N	Guidance did not cover acute complications for those living with thalassaemia. The Quality Standard was met for SCD.

Ref	Standard	Met Y/N	Reviewer comment
HC-510	**Clinical Guidelines: Chronic Complications** Guidelines on the management of the chronic complications listed below should be in use covering at least: I. Local management II. Indications for discussion at the HCC MDT III. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred IV. Arrangements for specialist multidisciplinary review a. Renal disease, including sickle nephropathy b. Orthopaedic problems, including the management of sickle and thalassaemia-related bone disease c. Eye problems, including sickle retinopathy and chelation-related eye disease d. Cardiological complications, including sickle cardiomyopathy and iron overload related heart disease e. Chronic respiratory disease, including sickle lung disease and obstructive sleep apnoea f. Endocrine and growth problems, including endocrinopathies and osteoporosis g. Neurological complications, including sickle vasculopathy, other complications requiring neurology or neurosurgical input and access to interventional and neuroradiology h. Hepatobiliary disease, including sickle hepatopathy, viral liver disease and iron overload-related liver disease i. Growth delay/delayed puberty j. Enuresis k. Urological complications, including priapism l. Dental problems	N	Guidance did not cover acute complications for those living with Thalassaemia. l' Dental was not covered in the WLHCC Paediatric Sickle Cell Guidance.
HC-511	**Anaesthesia and Surgery** Guidelines should be in use covering the care of children and young people with sickle cell disorder and thalassaemia during anaesthesia and surgery.	Y	
HC-599	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, admission units, clinic and ward areas.	Y	Staff could access guidance on the EOLOS APP.

Ref	Standard	Met Y/N	Reviewer comment
HC-601	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by an HCC / SHT b. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission c. Patient discussion at local multidisciplinary team meetings (QS HC-604) d. Referral of children for TCD screening if not provided locally e. 'Fail-safe' arrangements for ensuring all children and young people have TCD ultrasound when indicated f. Arrangements for liaison with community paediatricians and with schools or colleges g. Follow up of patients who 'were not brought' h. Transfer of care of patients who move to another area, including communication with all haemoglobinopathy services involved with their care before the move and communication and transfer of clinical information to the HCC, SHT, LHT and community services who will be taking over their care i. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together j. Governance arrangements for providing consultations, assessments and therapeutic interventions virtually, in the home or in informal locations	N	Due to the Trust having insufficient staff to deliver a consultant led-service, some support was by the paediatric haematology team at St Mary's via an agreed SLA. 'b' was not met as patients were not always seen by haematology senior haematology decision-maker within 14 hours of acute admission. Patients were seen by a general paediatrician. The paediatric haematology service (including haemoglobinopathies) and provision of paediatric apheresis was on the risk register The SOP seen would cover the the requirements of the QS if the service was provided in full by the trust.

Ref	Standard	Met Y/N	Reviewer comment
HC-603	**Shared Care Agreement with LHTs** A written agreement should be in place with each LHT covering: a. Whether or not annual reviews are delegated to the LHT b. New patient and annual review guidelines (QS HC-502) (if annual reviews are delegated) c. LHT management and referral guidelines (QS HC-503) d. National Haemoglobinopathy Registry data collection (QS HC-701) e. Two-way communication of patient information between HCC/SHT and LHT f. Attendance at HCC business meetings (HC-607) (if applicable) g. Participation in HCC-agreed audits (HC-706)	N	There were no formal shared care agreements in place with linked LHTs. In practice the SHT did have good working relationships with LHTs.
HC-604	**Local Multidisciplinary Meetings** MDT meetings to discuss and review patient care should be held regularly, involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, psychology staff and, when required, representatives of support services (QS HC-301).	Y	Weekly MDTS were in place with an agreed criteria for discussion.
HC-606	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of children and young people with haemoglobin disorders b. Two-way exchange of information between hospital and community services	N	The SHT did not have any SLAs with community services who were providing care for those children and young people with haemoglobin disorders.
HC-607 S	**HCC Business Meeting Attendance (SCD)** At least one representative of the team should attend each HCC Business Meeting (QS HC-702).	N	Due to workforce shortages a member of the paediatric SHT had not been able to attend all the WLHCC Business meetings.
HC-607 T	**HCC Business Meeting Attendance -Th)** At least one representative of the team should attend each HCC Business Meeting (QS HC-702).	N	Due to workforce shortages a member of the paediatric SHT had not been able to attend all the TRCNHCC Business meetings.

Ref	Standard	Met Y/N	Reviewer comment
HC-608	**Neonatal Screening Programme Review Meetings** The SHT should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results, identify issues of mutual concern and agree action.	N	Neonatal screening review meetings had not been implemented
HC-701	**National Haemoglobinopathy Registry** Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies, patients lost to follow up and the number of patients who have asked to have their name removed.	N	The SHT did not have data support for NHR.
HC-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HC-505) b. Acute admissions to inappropriate settings, including feedback from children, young people and their families and clinical feedback on these admissions	N	Due to insufficient resources, audits as required by the QS had not yet been undertaken.
HC-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS H-702d).	N	Due to insufficient resources, audits as required by the QS had not yet been undertaken.
HC-707	**Research** The service should actively participate in HCC-agreed research trials	N	The SHT did not have sufficient resources to engage with research. The team hoped that when workforces issues were resolved they would be able to engage with research with support from the paediatric clinical research facilities and access to support from the South Thames Paediatric Research Network.

Ref	Standard	Met Y/N	Reviewer comment
HC-797	**Review of Patient Experience and Clinical Outcomes** The service's multidisciplinary team, with patient and carer representatives, should review at least annually: a. Achievement of Quality Dashboard metrics compared with other services b. Achievement of Patient Survey results (QS HC-197) compared with other services c. Results of audits (QS HC-705): I. Timescales and pathway for regular transfusions II. Patients admitted to inappropriate settings Where necessary, actions to improve access, patient experience and clinical outcomes should be agreed. Implementation of these actions should be monitored.	N	The service's multidisciplinary team, with patient and carer representatives, had not been able to review 'a' or 'b'. Results of audits 'c' had not been undertaken so that comparisons could be made and discussed as defined by the QS.
HC-798	**Review and Learning** The service should have appropriate multidisciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, serious adverse events, incidents and 'near misses.'	Y	
HC-799	**Document Control** All information for children, young people and their families, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

Quality Standards – Care of Adults

Ref	Standard	Met Y/N	Reviewer comment
HA-101	**Haemoglobin Disorder Service Information** Written information should be offered to patients and their carers, and should be easily available within patient areas, covering at least: a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Contact interpreter and advocacy services, Patient Advice and Liaison Service (PALS), spiritual support and Healthwatch (or equivalent) v. Give feedback on the service, including how to make a complaint vi. Get involved in improving services (QS HA-199)	Y	

Ref	Standard	Met Y/N	Reviewer comment
HA-102	**Information about Haemoglobin Disorders** Patients and their carers should be offered written information, or written guidance on where to access information, covering at least: a. A description of their condition (SCD or Th), how it might affect them and treatment available b. Inheritance of the condition and implications for fertility c. Problems, symptoms and signs for which emergency advice should be sought d. How to manage pain at home (SCD only) e. Transfusion and iron chelation f. Possible complications g. Health promotion, including: i. Travel advice ii. Vaccination advice National Haemoglobinopathy Registry, its purpose and benefits Self-administration of medications and infusions	Y	
HA-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Planned acute and long-term management of their condition, including medication iii. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed The care plan and details of any changes should be copied to the patient's GP and their local team consultant (if applicable).	Y	
HA-104	**What to Do in an Emergency?** All patients should be offered information about what to do in an emergency covering at least: a. Where to go in an emergency b. Pain relief and usual baseline oxygen level, if abnormal (SCD only)	Y	

Ref	Standard	Met Y/N	Reviewer comment
HA-105	**Information for Primary Health Care Team** Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD) b. Side effects of medication, including chelator agents (SCD and Th) c. Guidance for GPs on: i. Immunisations ii. Contraception and sexual health d. What to do in an emergency e. Indications and arrangements for seeking advice from the specialist service	Y	
HA-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders.	Y	
HA-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care f. Advice for young people leaving home or studying away from home including: i. Registering with a GP ii. How to access emergency and routine care iii. How to access support from their specialist service iv. Communication with their new GP	Y	The Quality Standards was achieved however the documented names in guidelines did not reflect the current staff in post and therefore the review team recommended a further review or to adapt the guidance to reflect posts and not staff names. There was also a need to review with the pending changing ICU admission criteria to 16+ years.
HA-197	**Gathering Patients' and Carers' Views** The service should gather patients' and carers' views at least every three years using: 'Patient Survey for Adults with a Sickle Cell Disorder' UKTS Survey for Adults living with Thalassaemia	Y	

Ref	Standard	Met Y/N	Reviewer comment
HA-199	**Involving Patients and Carers** The service's involvement of patients and carers should include: a. Mechanisms for receiving feedback b. Mechanisms for involving patients and their carers in: i. Decisions about the organisation of the service ii. Discussion of patient experience and clinical outcomes (QS HA-797) Examples of changes made as a result of feedback and involvement	Y	
HA-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	Y	
HA-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services c. Competences in caring for people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	N	A Lead Nurse had been appointed and due to commence in post April 2025 however, this was only an. 18-month fixed term contract.
HA-204	**Medical Staffing and Competences: Clinics and Regular Reviews** The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	Y	

Ref	Standard	Met Y/N	Reviewer comment
HA-205	**Medical Staffing and Competences: Unscheduled Care** 24/7 consultant and junior staffing for unscheduled care should be available. SHTs and HCCs only: A consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients during normal working hours. Cover for absences should be available.	Y	
HA-206	**Doctors in Training** If doctors in training are part of achieving QSs HA-204 or HA-205 then they should have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y	
HA-207	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Clinical nurse specialist(s) with responsibility for the acute service b. Clinical nurse specialist(s) with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	Y	
HA-208	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders, including: a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multidisciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuropsychology Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	Y	

Ref	Standard	Met Y/N	Reviewer comment
HA-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	Y	
HA-301	**Support Services** Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HA-602) as required: a. Social worker / benefits adviser b. Leg ulcer service c. Dietetics d. Physiotherapy (inpatient and community-based) e. Occupational therapy f. Mental health services	N	Patients did not have timely or sufficient access to dietetic support.
HA-302	**Specialist Support** Access to the following specialist staff and services should be easily available: a. DNA studies b. Genetic counselling c. Sleep studies d. Diagnostic radiology e. Manual exchange transfusion (24/7) f. Automated red cell exchange transfusion (24/7) g. Pain team including specialist monitoring of patients with complex analgesia needs h. Level 2 and 3 critical care	Y	
HA-303	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y	
HA-304	**Urgent Care – Staff Competences** Medical and nursing staff working in Emergency Departments and admission units should have competences in urgent care of people with haemoglobin disorders.	Y	

Ref	Standard	Met Y/N	Reviewer comment
HA-501	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their family or carer, paediatric and adult services, primary health care and social care in planning the transfer, including a joint meeting to plan the transfer of care c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between HCCs, SHTs and LHTs (if applicable) h. Responsibilities for giving information to the young person and their family or carer (QS HA-195)	N	Transition guidelines were in place but had not been fully implemented ('f 'g' and 'h')
HA-502	**New Patient and Annual Review Guidelines** Guidelines or templates should be in use covering: a. First outpatient appointment b. Annual review Guidelines should cover both clinical practice and information for patients and carers.	Y	

Ref	Standard	Met Y/N	Reviewer comment
HA-505	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: i. Emergency and regular transfusion ii. Use of simple or exchange transfusion iii. Offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for: i. Manual exchange transfusion ii. Automated exchange transfusion on site or organised by another provider c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts e. Patient pathway and expected timescales for regular transfusions, including availability of out of hours services (where appropriate) and expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion f. Patient pathway for Central Venous Access Device insertion, management and removal	Y	
HA-506	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug(s), dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Self-administration of medications and infusions and encouraging patient and carer involvement in monitoring wherever possible	N	TRCN guidance did not cover 'f' self-administration of medications and appendix 2 for local contacts had not been completed

Ref	Standard	Met Y/N	Reviewer comment
HA-507	**Hydroxycarbamide and Other Disease Modifying Therapies** Guidelines on hydroxycarbamide and other disease modifying therapies should be in use covering: a. Indications for initiation b. Monitoring of compliance and clinical response, including achieving maximum tolerated dose for hydroxycarbamide c. Documenting reasons for non-compliance d. Monitoring of complications e. Indications for discontinuation	Y	
HA-508	**Non-Transfusion Dependent Thalassaemia (nTDT)** Guidelines on the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy d. Consideration of options for disease modifying therapy	N	The TRCN guidelines had not had Appendix 2 amended for use locally.
HA-509	**Clinical Guidelines: Acute Complications** Guidelines on the management of the acute complications listed below should be in use covering at least: i. Local management ii. Indications for seeking advice from the HCC/SHT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred For patients with sickle cell disorder: a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision For patients with thalassaemia: k. Fever, infection and overwhelming sepsis l. Cardiac, hepatic or endocrine decompensation	N	The TRCN guidelines had not had Appendix 2 amended for use locally. The WLSCD HCC sickle cell guidance did meet the requirements of the QS.

Ref	Standard	Met Y/N	Reviewer comment
HA-510	**Clinical Guidelines: Chronic Complications** Guidelines on the management of the chronic complications listed below should be in use covering at least: i. Local management ii. Indications for discussion at the HCC MDT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred iv. Arrangements for specialist multidisciplinary review a. Renal disease, including sickle nephropathy b. Orthopaedic problems, including the management of sickle and thalassaemia-related bone disease c. Eye problems, including sickle retinopathy and chelation-related eye disease d. Cardiological complications, including sickle cardiomyopathy and iron overload related heart disease e. Pulmonary hypertension f. Chronic respiratory disease, including sickle lung disease and obstructive sleep apnoea g. Endocrine problems, including endocrinopathies and osteoporosis h. Neurological complications, including sickle vasculopathy, other complications requiring neurology or neurosurgical input and access to interventional and neuroradiology i. Chronic pain j. Hepatobiliary disease, including sickle hepatopathy, viral liver disease and iron overload-related liver disease k. Urological complications, including priapism and erectile dysfunction l. Dental problems	N	'l' Dental was not covered in the WLHCC guidance. TRCN guidelines -Appendix 2 had not yet been amended for use locally
HA-511	**Anaesthesia and Surgery** Guidelines should be in use covering the care of patients with sickle cell disorder and thalassaemia during anaesthesia and surgery.	Y	

Ref	Standard	Met Y/N	Reviewer comment
HA-512	**Fertility and Pregnancy** Guidelines should be in use covering: a. Fertility, including fertility preservation, assisted conception and pre-implantation genetic diagnosis b. Care during pregnancy and delivery c. Post-partum care of the mother and baby Guidelines should cover: i. Arrangements for shared care with a consultant obstetrician with an interest in the care of people with haemoglobin disorders, including details of the service concerned ii. Arrangements for access to anaesthetists with an interest in the management of high-risk pregnancy and delivery iii. Arrangements for access to special care or neonatal intensive care, if required iv. Indications for discussion at the HCC MDT (QS HA-605) v. Arrangements for care of pregnant young women aged under 18	Y	
HA-599	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, admission units, clinic and ward areas.	Y	

Ref	Standard	Met Y/N	Reviewer comment
HA-601	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission b. Patient discussion at local multidisciplinary team meetings (QS HA-604) c. Follow up of patients who 'did not attend' d. Transfer of care of patients who move to another area, including communication with all haemoglobinopathy services involved with their care before the move and communication and transfer of clinical information to the HCC, SHT, LHT and community services who will be taking over their care e. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together f. Governance arrangements for providing consultations, assessments and therapeutic interventions virtually, in the home or in informal locations	Y	
HA-603	**Shared Care Agreement with LHTs** A written agreement should be in place with each LHT covering: a. Whether or not annual reviews are delegated to the LHT b. New patient and annual review guidelines (QS HA-502) (if annual reviews are delegated) c. LHT management and referral guidelines (QS HA-503) d. National Haemoglobinopathy Registry data collection (QS HA-701) e. Two-way communication of patient information between HCC/SHT and LHT f. Attendance at HCC business meetings (HA-607) (if applicable) g. Participation in HCC-agreed audits (HA-706)	N	The Epsom and St Helier SLA was in draft. There was no shared care agreement in place with the LHT based at Frimley Park.
HA-604	**Local Multidisciplinary Meetings** MDT meetings to discuss and review patient care should be held regularly, involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, psychology staff and, when requested, representatives of support services (QS HA-301).	Y	

Ref	Standard	Met Y/N	Reviewer comment
HA-606	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	N	Services provided by Central London Community Healthcare (CLCH). No SLA with St Georges was seen covering the requirements of the QS.
HA-607 S	**HCC Business Meeting Attendance (SCD)** At least one representative of the team should attend each HCC Business Meeting (QS HA-702).	Y	
HA-607 T	**HCC Business Meeting Attendance (Th)** At least one representative of the team should attend each HCC Business Meeting (QS HA-702).	N	Attendance at 2 out of 5 meetings since February 23. The review team felt that this was not regular enough to achieve the standard.
HA-701	**National Haemoglobinopathy Registry** Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies, patients lost to follow up and the number of patients who have asked to have their name removed.	Y	
HA-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HA-505) b. Acute admissions to inappropriate settings, including patient and clinical feedback on these admissions	Y	
HA-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS H-702d).	Y	
HA-707	**Research** The service should actively participate in HCC-agreed research trials.	Y	

Ref	Standard	Met Y/N	Reviewer comment
HA-797	**Review of Patient Experience and Clinical Outcomes** The service's multidisciplinary team, with patient and carer representatives, should review at least annually: a. Achievement of Quality Dashboard metrics compared with other services b. Achievement of Patient Survey results (QS HA-197) compared with other services c. Results of audits (QS HA-705): i. Timescales and pathway for regular transfusions ii. Patients admitted to inappropriate settings Where necessary, actions to improve access, patient experience and clinical outcomes should be agreed. Implementation of these actions should be monitored.	N	The review team felt that there was a need to develop a clear method to meet these requirements of review within the SHT.
HA-798	**Review and Learning** The service should have appropriate multidisciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, serious adverse events, incidents and 'near misses'.	Y	
HA-799	**Document Control** All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

Appendix 3 Immediate Risk Actions

Trust and UKFHD Steering Group Responses

Response from Trust received 2nd April 2025:

Background to the concerns

After a period of stability with 3 consultants (2.5wte) in February 2023 – July 2023, one consultant colleague made the decision to go back into training and left the Trust. The position was put out to advert, but we were unable to recruit. Prior to this recruitment cycle we had started extensive discussions with tertiary partners to mitigate the risk to the service from the gap. However, in October 2023 one of the remaining consultants went on maternity leave followed by the remaining consultant going on sickness related leave in November 2023, which left the service without a consultant.

Following meetings between senior trust leadership, commissioners and partners, Imperial College Healthcare NHS Trust agreed to provide support to us and our SW London and Surrey referral centres while further recruitment drives continued, including overseas. The Trust worked with the GMC to try and expedite registration for an overseas appointee in early 2024 but this candidate then withdrew in August 2024. At the time it was decided not to put out the advert again as, following three rounds of unsuccessful interviews, it seemed clear that we would not be successful in filling this position in its current form.

In light of the significant risk to the service, an external agency was used to source a paediatric haematologist who covered the role from February to May 2024 but this person then declined further agency work. One consultant returned from sick leave in February 2024 and the gap was further mitigated by additional support from a senior general paediatric consultant with expertise in haemoglobinopathy with ongoing support from specialist services at Imperial. The second consultant returned from maternity leave in February 2025.

Addressing immediate safety concerns

We have taken the following steps to address the immediate concerns you have outlined, which we have identified as below:

We recognise that there will be additional fragility until the end of June 2025 while the general paediatric consultant with expertise in haemoglobinopathy is on career break. A comprehensive SLA with Imperial has been signed until end of June 2025 to cover gaps within the service and accept calls from our referring network hospitals 24/7.

We have already begun discussions with Imperial College Healthcare NHS Trust to scope capacity for a joint service across the region. A first step in this will be a joint appointment, which we anticipate will greatly increase the success of recruiting to the vacant PAs.

As an additional mitigation, the Head of Nursing for Children's services has begun discussions with her counterpart at Imperial to explore whether they can provide specialist nursing support for the vacant CNS core hours.

The clinical director has met with the two paediatric haematology consultants to agree job plans for the coming year and the requirement for Monday cover to form part of core activity. This will be supported in the short term by the SLA with Imperial, which includes Monday cover.

We are starting discussion with the adult haemoglobinopathy service to see what internal support or ways of working can be instituted across the week to build further resilience into the service, including more robust haematology resident doctor support and appropriate nursing support.

As outlined above, high level discussions with Imperial College Healthcare NHS Trust have begun to consider the development of a joint service. There are multiple variables which are being clearly outlined in a formal options appraisal. This will include the impact on the adult haemoglobin disorders pathway, and the option and feasibility

of an all-age service at St George's. This will be ready for presentation to the Executive team of the trust by May 2025.

We recognise that there are significant risks in this service in its current form. We will continue to monitor this closely and ensure that there are sufficient mitigations in place to maintain clinical safety and understand the impact on patients and staff while difficult decisions about the future of the service are made.

UKFHD Peer Review Steering Group response sent 9th April 2025:

Thank you for your letter 2nd April 2025 outlining the actions you are taking to mitigate the immediate risk to clinical safety or clinical outcomes as identified to your staff at the end of the visit on the 21st March 2025.

The Clinical Leads have reviewed your response and consider the actions being taken in the interim are appropriate and note your timescale for completing and presenting to the Executive Team the formal optional appraisal by May 2025.

The UKFHD Steering Group would be grateful if they could receive an update on progress with regards to the actions outlined in your letter at the beginning of June in order that they can be considered at UKHD Peer Review Steering Group meeting scheduled for June.

Response from Trust received 23rd June 202: Update to UKFHD Steering Group on progress

Thank you for your letter of 8th April 2025 requesting an update on progress in early June with regards to actions to mitigate the immediate risk identified in the paediatric haemoglobinopathy service at St George's.

The immediate safety concern was a lack of Specialist Haemoglobinopathy Team (SHT) consultant cover for the St George's site on a Monday. This has now been addressed and the two SHT consultants provide cover 9-5 Monday to Friday on a rota.

In addition, we have strengthened our out of hours support by working with Imperial College Healthcare NHS Trust (ICHT). A networked out of hours rota will be in place from 31.7.25 for specialist paediatric haematology advice out of hours with the SHT at ICHT. The first tier of this at St George's will be with the haematology resident doctors currently rotating through the adult haematology service. They will provide additional on-site haematology advice for the paediatric service, linking in with the paediatric SHT consultant in the network as needed.

There remains limited resilience within the SHT as we only have two substantive consultants in post, both working less than full time. However, there has been agreement with ICHT that we will jointly fund a post to provide 6PAs of SHT consultant input for St George's, increasing our team to just under 2 Whole Time equivalents. The post is currently going through site level vacancy controls and we should be in a position to update on this by the end of the Summer. We recognise that previous recruitment has been unsuccessful, but we anticipate that this joint post will provide an attractive role. There remains work to do on understanding the remaining gap and the funded establishment which we continue to explore, recognising also the interdependencies with other paediatric haematology services at St George's. An options appraisal is being prepared for the Executive team to consider this.

With regards to nursing cover, internal cross cover from the other Paediatric Haematology CNS (bleeding disorders) will provide some cover on Monday and Friday for the vacant CNS core hours. Discussions are ongoing with ICHT around options for networked specialist nursing support.

The above actions continue to mitigate the most immediate risks. However, we recognise that there continues to be a risk to the sustainability of the service in the longer term.