



# Health Services for People with Haemoglobin Disorders

## Homerton Healthcare NHS Foundation Trust

Visit Date: 18<sup>th</sup> June 2025

Report Date: 27<sup>th</sup> October 2025

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## Introduction

This report presents the findings of the review of Homerton Healthcare NHS Foundation Trust (HH) that took place on 18<sup>th</sup> June 2025.

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 Homerton University Hospital 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:

- Homerton Healthcare NHS Foundation Trust
- NHS England, London
- North East 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 approaches; some require commissioner input. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place and monitoring their implementation, liaising, as appropriate, with other commissioners, including commissioners of primary care. The lead commissioners in relation to this report are NHS England London region and North East 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 UKFHD 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 UKFHD is to, advocate and influence policy, promote and review best practice, share ideas and advise on research, educate health

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

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 Homerton Healthcare 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

### Homerton Healthcare NHS Foundation Trust

#### Trust-wide General Comments

This review looked at the health services provided for adults with haemoglobin disorders at Homerton Healthcare NHS Foundation Trust (HH). In total the trust served 444 adults living with Haemoglobin Disorders, split by 420 people living with a Sickle Cell Disorder (SCD) 17 people living with Thalassaemia, and seven people living with a rare inherited anaemia. During the visit, the reviewers attended the Homerton University Hospital site and visited the emergency department, assessment unit, medical day unit and wards; they met with patients and carers before and during the visit, and with staff providing services for the local health economy.

Homerton Healthcare NHS Foundation is an integrated care trust which provides hospital and community health services for Hackney, City and the surrounding communities. Homerton Healthcare NHSFT was part of the East London and Essex Haemoglobinopathy Sickle Cell Coordinating Centre and the London and South East Thalassaemia and Rare Inherited Anaemia HCC (both hosted by Barts Health NHS Trust).

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.

#### Trust -wide Good Practice

Reviewers identified a number of areas of good practice in the care of adults living with haemoglobin disorders which are detailed in the adult section of the report.

#### Trust -wide Immediate Risks

##### 1. Sustainability of the Specialist Haemoglobinopathy Team<sup>1</sup>

Despite the actions taken by the Trust to maintain the Specialist Haemoglobinopathy Team (SHT) service provided by the Trust, reviewers were extremely concerned about the continued fragility and vulnerability of the haemoglobinopathy service, and the culmination of issues that were impacting on the clinical safety and clinical outcomes of adults and young people with haemoglobin disorders cared for by the trust at the time of the visit for the following reasons: -

- a. There were insufficient consultant staff with specialist experience in the care of adults and young people with haemoglobin disorders on site to provide scheduled and emergency care for the 444 patients under the care of Homerton.
  - i. The Trust had three unfilled substantive consultant haematologist posts.
  - ii. The SHT had an interim Lead Consultant who had four programme activities (PAs) for all haemoglobinopathy work with little time for leadership of the SHT.
  - iii. Two locum consultant haematologists had a total of three PAs allocated for haemoglobinopathy work, however one of the locum consultants was leaving to take up a substantive post..
  - iv. A service level agreement, which had commenced in April 2025, with Barts Health NHS Trust to provide three PAs of Consultant Haematologist time for specialist haemoglobinopathy work (clinics and MDTs) was a temporary arrangement for 18 months and would not be a sustainable option for

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<sup>1</sup> The immediate risk is included in the Trust wide section as well as in the Adult SHT section of the report.

the future. Barts Health is also experiencing challenges around consultant staffing meaning there is pressure across the entire North East London sector in this respect.

- v. In total this only amounted to 10 PAs of consultant haemoglobinopathy time for the SHT. This is below the recommended number.
- b. Temporary arrangements for additional out of hours specialist advice and support were also in place provided by Barts Health NHS Trust and Barking, Havering and Redbridge NHS Trust.
- c. The SHT service was closed to new patient referrals and the provision of specialist care to their three linked Local Haemoglobinopathy Teams (LHTs) had been suspended with all activity being diverted to the SHT at Barts Health. This had resulted in young people within the City and Hackney area being unable to transition to their nearest adult service and access the provisions of the SHT. Prior to this the SHT had seen a 9-10% increase per year in patient numbers and increasing complexity and acuity of this patient group.
- d. An Advanced Nurse Practitioner had been appointed to support all clinical activity, but utilising the existing consultant haematologist funding, which will potentially impact on the available funding for the consultant haematologist workforce in the future.
- e. Much of the oversight and governance of the SHT was dependant on the Nurse Consultant in addition to the clinical aspects of their role. The SHT also had a highly dedicated and expert senior nursing team who, due to the medical workforce shortages, were overstretched taking on additional coordination of patient care and undertaking non role appropriate work. Reviewers were concerned at the ongoing pressure the senior nursing team were experiencing.
- f. The SHT had no data support for audit or data submissions to the NHR or NHSE Specialised Services Quality Dashboard (SSQD). Reviewers were told that data to the SSQD had not been submitted for two years despite requests from NHSE. Completion of the SSQD is a requirement within the NHSE SHT specification as submission provides assurance on the quality of care and patient outcomes to commissioners. The potential impact of non-submission could impact on continued SHT funding and recognition as a specialist haemoglobinopathy team.
- g. The risk to adults had been identified and documented on the Trust risk register, however from discussions with the representative from the specialist services team at North East London ICB this had not been highlighted with them, possibly as the main trust links were with the contracts team at the NEL ICB.
- h. The SHT were not part of the Pan London Sickle Improvement Project meetings and therefore had missed opportunities for additional funding.

As part of discussions about the serious issues faced by the SHT during the visit, reviewers were asked to identify any actions which could be implemented which would optimise the clinical time available, reduce the stress being experienced by the senior nursing team and provide more quality assurance and improved governance: -

- Access to a specific data manager to assist with data collection and entry as well as undertaking specific quality assurance audits would allow the senior nurses to focus on clinical care and service development and ensure appropriate quality assurance reporting.
- Increasing the specific service management capacity dedicated to the haemoglobinopathy service could also relieve the senior nurses of some of their non-clinical responsibilities.

## Trust -wide Serious Concerns

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

## Trust-wide Concern

**Trust-wide concern- Adults:** See adult section of the report for more detail.

### 1. SHT Senior Nursing Workload

Reviewers were concerned about the workload of the Nurse Consultant, ANP and CNSs who were working in extenuating circumstances and working well above their contracted hours to ensure patient safety and wellbeing was maintained.

### 2. Access to Psychology

Based on the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation one WTE clinical health Psychologist for 300 patients, at the time of the visit there was insufficient psychology provision (0.8WTE) to care for the 444 patients under the care of the SHT.

### 3. Transition

Prior to reinstatement of transition of young people to the adult SHT at the Trust, work will be required to re-establish a transition pathway and to ensure there is sufficient staffing in the adult and paediatric teams to provide appropriate support and facilitation to enable the safe transitioning of young people living with a haemoglobin disorder.

### 4. Guidelines

Due to the workload of the SHT, many of the recommended guidelines were in draft form or out of date.

### 5. High Non- attendance Rates at Clinics

The SHT were experiencing a high non-attendance rate (DNA) of patients attending outpatient clinics despite patients being contacted on the day of their appointment by the CNSs.

## Trust-Wide Further Consideration

1. Patients who met with the visiting team reported difficulties in receiving timely analgesia when attending the ED. The issue had also been discussed at one of the joint staff and patient group meeting when patients had been told that the Trust were working to improve the compliance with the NICE guidance; Sickle Cell Disease: managing acute painful episodes in hospital.

At the time of the visit an audit was in progress but was not yet completed and estimated compliance was about 50% from the initial data collected. Reviewers were made aware of a range of actions being taken by the SHT to improve the urgent and emergency pathway to improve compliance with the time to first dose of analgesia however if the early results transpired to be correct then compliance with the guidance was suboptimal.

### Views of Service Users and Carers

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

The visiting team held focus groups prior to the visit during the visit, and in total met eleven adults living with a Sickle Cell Disorder (SCD), a carer of a person living with SCD and one adult living with Thalassaemia. The views of the users were extensive and wide-ranging and are documented in the adult specialist haemoglobinopathy team section.

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

## Specialist Haemoglobinopathy Team (Adult Services)

### General Comments and Achievements

This was an extremely hardworking, innovative and committed SHT who had been working in challenging circumstances for a number of years, and the SHT had good support from their directorate management team.

The Specialist Haemoglobinopathy Team (SHT) provided some specialist advice to three Local Haemoglobinopathy Teams (LHTs) based at Basildon University Hospital and Southend University (Mid Essex Hospital Services NHS Trust) and Colchester Hospital NHS Foundation Trust (East Suffolk and North Essex NHS Foundation Trust).

At the end of 2023, the service faced the sudden and tragic loss of its lead haemoglobinopathy consultant, significantly impacting staffing and service delivery. In response, the team and Trust had implemented a number of operational measures to mitigate the impact of the reduction in the consultant haematologist workforce to ensure the safe and effective care of their patient cohort, whilst also exploring new approaches to support service delivery. With a dedicated and highly skilled nursing workforce, the service had adopted a hybrid model of working.

Since January 2024 the provision of LHT care by the HH SHT had been suspended and patients at the LHTs based at Basildon University Hospital, Southend University Hospital and Colchester Hospital NHS Foundation Trust had their specialist care overseen by the adult SHT based at the Royal London Hospital (RLH). The SHT at HH had however continued to provide regular access to automated Red Cell Exchange treatments (aRCE), clinic reviews and advice for patients based in Essex operational delivery network (ODN) and had continued to oversee patients where shared care had already been established. Prior to these mitigating actions (until the end of 2023) the HH SHT, had continued to see a 9-10% increase per year in patient numbers with the associated activity.

The HH SHT had an interim Lead Consultant Haematologist and worked as an integrated acute and community multidisciplinary team. Recruitment was underway for a Consultant Haematologist as a joint appointment with Barts Health NHS Trust (eight PAs at HH and two PAs at RLH). A Service Level Agreement (SLA) had been implemented since April 2025, providing additional specialist haematology input for clinics, MDTs and quality and governance processes (three PAs per week), from Barts Health. At the time of the visit the SHT service remained closed to new patient referrals to ensure consistent and safe care for the existing patient group. Reviewers were told that the SHT hoped to reopen to new referrals as soon there was an additional substantive consultant in post.

All children resident in London Borough of Hackney attended the paediatric SHT based at the Royal London Hospital (Barts Health NHS Trust), and when appropriate young adults had been transitioned for ongoing care to the adult SHT team at HH. At the time of the visit, due to the staffing challenges, the transitioning of young people to the SHT at HH had been suspended and young people were transitioned for their specialist adult care to the SHT based at the Royal London Hospital.

Patients could access ambulatory care in the ED or MDU up to twice per week, provided these visits did not occur in consecutive weeks. Any presentations beyond this threshold required a senior review and could indicate the need for hospital admission for further management and investigation. The rationale behind this pathway was that it allowed the SHT to appropriately assess patients, as attendance beyond the above criteria, could reflect either inappropriate treatment of chronic pain or inadequate treatment of more severe crises that required admission for further management. *See also patient feedback about this pathway.*

The MDU and ED nursing teams had been piloting Patient Group Directions (PGDs) to initiate some medications and analgesia promptly following assessment. In the ED all experienced Band 5 nurses and above and in the MDU all Band 6 nurses and above had been trained to deliver the PGDs. This initiative aimed to enhance the patient pathway, reduce the time to effective pain relief and improve the overall patient experience. The project

was in its early stages and was set to undergo its first review within the next two months. Patients who met with the visiting team valued this initiative.

Haemoglobinopathy multidisciplinary team meetings were held every two weeks and in addition to the SHT members included representation from ED staff.

## **Integrated Acute and Community-based Care**

The Sickle Cell and Thalassaemia service at HH was an integrated service covering both acute and community services. It was impressive that nursing staff within the service rotated across multiple sites that ensured seamless integration between inpatient and community services.

The service was supported by a comprehensive multidisciplinary team, consisting of a Nurse Consultant, Advanced Clinical Practitioner (ACP), Senior Clinical Nurse Specialist (CNS) and three Adult CNS, two Paediatric CNSs, Psychotherapist, Social Liaison Advisor, Welfare and Benefits Advisor and Centre Administrator.

The nurse consultant provided highly specialised clinical leadership, guidance, and strategic direction for the service. As part of their responsibilities, they undertook ward rounds, complex patient reviews, advised on local policies, lead on staff training across the borough, and contributed to research and strategic oversight for service development. The nurse consultant had also been involved in the development of the RCN competence framework for haemoglobin disorders which was published in 2024.

The ACP role was a relatively new role which had been implemented as part of the Trust actions to address the shortfall in the medical workforce utilising existing funding from one of the three vacant consultant haematologist posts. The ACP supported all clinical activity including ward rounds, nurse led clinic and promoting patient autonomy and wellbeing.

The CNSs within the team would follow up patients on discharge from hospital as well as ad hoc, for primary care engagement. This included medicines management, health reviews and pre/post hospital assessments. The CNSs provided support for patients and their families advocating for care close to home, improved patient access to services and promoting a reduction in health inequalities. The adult and paediatric CNSs would participate in relation to transition. The Paediatric CNSs engaged with RLH on clinic days and during regular patient MDTs.

The social liaison team provided support to patients and their families with a variety of different focuses including education and employment, benefits, as well as general advice. The social liaison team were active in raising awareness of sickle cell & thalassaemia disorders within the local community and provided training and support for social care teams and housing services.

The psychology post was vacant at the time of the visit with the new postholder due to commence in role shortly after the visit. A psychotherapist (0.4WTE) was in post to support patients with their emotional and mental wellbeing. Patients could self-refer or be formally referred to the service.

The team had well-established pathways within the primary care setting for acute and chronic disorder management. The team had fostered good relationships with the local ICB and GP network and regular training and development sessions were delivered and reported as attracting high engagement from GPs and patient representatives, who actively participated in these sessions. The education sessions were available on the City & Hackney GP website for further reference and information alongside the clinical pathways.

The service was responsible for processing all affected or carrier new-born blood spot results in conjunction with Central Middlesex screening laboratory. The team was responsible for routine and pre-conceptual screening including referrals for PGT-M (pre-implantation genetic testing for monogenic disorders).

SPECIALIST HAEMOGLOBINOPATHY TEAM- ADULT <sup>2</sup>							
Homerton University Hospital		Linked Haemoglobinopathy Coordinating Centres (HCC)					
		East London and Essex Sickle Cell HCC					
		London and South East Thalassaemia and Rare Inherited Anaemia HCC <i>(both hosted by Barts Health NHS Trust)</i>					
		Linked Local Haemoglobinopathy Teams LHT				Patient Distribution	
						SCD	Thalassaemia
		Mid Essex Hospital Services NHS Trust: -			<i>LHT care by the HH SHT had been suspended for new patients and these patients had their specialist care from the SHT based at the RLH SHT. Some LHT/SHT shared care was provided for existing patients at HH</i>		
		<ul style="list-style-type: none"> <li>Basildon University Hospital</li> <li>Southend University Hospital.</li> </ul>					
		East Suffolk and North Essex NHS Foundation Trust: -					
		<ul style="list-style-type: none"> <li>Colchester Hospital NHS Foundation Trust</li> </ul>					
PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM							
Condition		HH Registered patients	Active patients* <sup>3</sup>	Annual Review **	Long term transfusion	% Eligible patients on hydroxycarbamide	Inpatient admissions in the last year
Sickle Cell Disorder	Adults	420	400	69	96	76	551
Thalassaemia and RIA	Adults	24	22		6	<=5	9

### 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		444	10 PA divided between all consultants in the department
Clinical Nurse Specialist dedicated to work with patients living with haemoglobinopathies in the acute and community service		444 Adults 140 Paeds – SLA RLH	4 wte Adult 1.5wte Paeds
Clinical Psychologist dedicated to work with patients living with haemoglobinopathies		444	0.8wte

### Urgent and Emergency Care

Patients had direct access to the Medical Day Unit (MDU) Monday to Friday between 9am and 3pm. On presentation to MDU they were seen by the haematology team. Patients who attended the ED would be referred to the MDU at 9am Monday to Friday for ongoing care.

Outside of normal working hours, including bank holidays and weekends patients would present to the Emergency Department (ED). The ED comprised of single room bedded areas, a 'pod' room where treatments could be administered and a 'fit to sit' area. The team had robust working relationships with ED and had a number of specific SOPs relating to treating patients with haemoglobinopathies in ED. The ED team were proactive in alerting the SHT when patients had attended the ED, and an automated flagging alert system to

<sup>2</sup> 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.

<sup>3</sup> \*Those who have had hospital contact in the last 12 months \*\* No of patients who have had an annual review in the last year.

inform the SHT service of any admissions was due to be implemented shortly after the visit. Members of the ED team also attended the Haemoglobinopathy MDT.

An audit of compliance with the NICE guidance for Sickle Cell Disease: managing painful episodes, was in progress.

Patients assessed and reviewed by the GP in a primary care setting followed an established pathway. This pathway outlined criteria for escalation and referral when inpatient management was required.

All patients had care plans (patient profiles). The patient profile included background information about the patient's condition and specific recommendations on their acute management. Patients who met with the visiting team commented that staff in the ED would access their care plan when they attended in an emergency. Patient profiles were available trust wide on the 'S Drive'. The drive was accessible to all clinicians within the trust but could only be edited by the haemoglobinopathy team. A copy of the patient profile had also been uploaded to the Universal Care Plan (UCP) platform (via EPR) should the patient present for treatment elsewhere.

## In-patient Care

Patients were admitted directly from the Medical Day Unit (MDU) or ED to the inpatient ward areas. In circumstances where there were no beds available patients were admitted to the acute care unit (ACU). The ACU was a 35 bedded acute general admissions unit.

Patients were initially admitted to inpatient services under the care of the on call medical team after which they were transferred to the haematology team. For those admitted via ACU, once an inpatient bed was available they would be transferred to one of the three wards identified to care for patients with haemoglobinopathies: Lloyd, Edith Cavell, or Lamb. Lloyd, Lamb and Edith Cavell wards were 28 bedded inpatient units.

Inpatient treatment regimens included a combination of both oral and parenteral protocols of care. Approximately 60% of patients utilised an oral only protocol with the remainder opting for parenteral treatment consisting of either subcutaneous patient-controlled analgesia (PCA) or stat subcutaneous injections. The SHT had phased out the use of Diamorphine as first line analgesia treatment for those experiencing a vaso occlusive crisis in 2022. All patients had their preferred regime highlighted on their individualised patient profile.

The SHT had good relationships with the ITU ensuring rapid escalation pathways and early intervention. This included out-of-hours manual exchange, and assessment and early intervention from the Critical Care Outreach Team (CCOT) in inpatient areas. The service had implemented the regular use of Therapeutic Plasma Exchange as a treatment for Fat Emboli in patients with Sickle Cell Disorders across the network.

There was regular and ongoing collaboration to ensure teaching for all new nursing staff joining the inpatient wards to include haemoglobin disorder specific training. This also included the inpatient and ED doctors in training who were on rotation to these areas. The team were a fixed part of the RESPOND Patient deterioration study day for all staff across the trust. The study day occurred at consistent regular intervals throughout the year, with a specific focus on Sickle Cell Disorders and acute chest syndrome.

Inpatient admissions were reported as being an average of 550 per year and inpatient hospital days had been decreasing to about 2168 days with the average length of stay (LOS) for patients reported to be 3.9 days. It was perceived some of the reduction in inpatient activity was largely due to the use of attendance protocols and the increase in aRCE and hydroxycarbamide treatments.

## Day Care

The Medical Day Unit (MDU) was open from Monday to Friday 9am to 5pm. The day unit activity included both emergency and planned activity. With patients attending for ambulatory care when experiencing an acute crisis up to 3pm Monday to Friday and for planned procedures including blood transfusions and other treatment modalities 9am to 5 pm Monday to Friday.

The Medical Day Unit comprised of two areas: MDU 1 & MDU 2. The resource within these two areas as agreed with the MDU clinical team and CNSs from the specialties using these, had been established. MDU 1 had five chairs and three beds and MDU 2, six chairs and two beds. The activity data provided from April 2024 to March 2025, was 1,174 episodes of recorded activity on the unit for patients living with a Sickle Cell Disorder or Thalassaemia.

At the time of the visit there were 88 patients on aRCE and 14 patients on top-up units transfused and all patients had individualised blood transfusion protocols. The service had three automated red cell machines for aRCE/ Therapeutic Plasma Exchange (TPE). This had allowed for better patient access and the support of emergency procedures. The service was fully staffed by the MDU nursing team who had apheresis skills.

## Outpatients

Consultant-led haemoglobinopathy clinics were held every week. These were a combination of face-to-face or video/telephone appointments. Face to face clinics were held on Monday afternoons, Tuesday and Thursday mornings. (three PAs). Non face to face clinics were held on Tuesday afternoons. (one PA). Reviewers were told that patients were offered alternate face to face and telephone appointments, although they were experiencing high non-attendance rates despite patients being messaged before their appointment by the CNS team.

A joint haematology-obstetric clinic attended by a consultant haematologist and consultant obstetrician was run every four weeks. Pregnant patients living with a haemoglobin disorder were reviewed along with the haemoglobinopathy specialist midwife.

A joint haemoglobinopathy pain clinic was held every month and patients with complex pain were reviewed jointly by a consultant haematologist/nurse consultant and consultant anaesthetist with a special interest in pain management.

Nurse consultant led clinics were held weekly to review blood transfusion protocols, chelation therapy and complex patient reviews, including optimisation of medications.

Nurse-led specialist medicines clinic for hydroxycarbamide were run weekly (this previously included other disease modifying treatments prior to national withdrawal). The clinic was led by the Advanced Clinical Practitioner (ACP) in haemoglobinopathies with competencies in advanced practice including prescribing. This was overseen by the nurse consultant. At the time of the visit, 77 patients were accessing the nurse led clinics. Approximately 42% of the patient group were on disease modifying treatments.

## Views of Service Users and Carers

The visiting team held three virtual focus groups prior and met with patients during the visit, and in total met ten adults living with a Sickle Cell Disorder, a carer of a person living with a Sickle Cell Disorder and one adult living with Thalassaemia.

### Service User Feedback

#### Contacting the Team

- All praised the Nurse Consultant, ANP and the CNS team as being 'excellent' in the support they received, commenting that they provided 'personalised care, would listen', problem solve and coordinate their care.
- For non-emergency advice, patients valued being able to contact the team directly by text if they had any issues or they could telephone the Medical Day Unit.
- Some commented that they would tend to email if they were unwell but responses were not always timely.

#### Information Received

- They were all aware of how to access information about their condition and would receive information via text, at appointments or via national charities.

### **Access to welfare advice and support**

- Access to welfare information and advice was via the Sickle Cell Centre based locally.

### **GP Experience**

- All patients stated that their GPs also held copies of their care plans and clinical letters.

### **Access to Psychology**

- All were aware of the haematology mental health service and knew how to access and request a referral if required.

### **Care Plans**

- Most had care plans but those who met the reviewing team said that these had not been updated for some time, although they did not feel that their emergency care protocols had required updating. Some considered that their care plans were generic and would be of more value to them if they were more individualised.
- All commented that their care plans were accessible and followed by staff when then attended the ED.
- They were aware that Universal Care Plans (UCP) were being introduced and had submitted some information but thought that they were not yet in use.

### **Review Appointments**

- For the last few years follow up appointments at Homerton were telephone clinics and many had not seen a medical professional in a face to face setting for up to three years. They all would value having the option to attend in person for their reviews
- Some talked about the changes in medical staff and the subsequent lack of knowledge some medical staff had about their condition. One patient living with Thalassaemia had been required to remind the doctor that they did not need an emergency pain protocol as they were not living with a Sickle Cell Disorder. They commented that the changes in medical staff had meant that they had no one to liaise with who knew their history and they had lost confidence in their medical care. Others commented that follow up clinic appointments had been delayed and reported waiting for over a year for an appointment.
- For those who had complex pain they could be referred to the pain clinic although they talked about appointments for the clinic being cancelled on a regular basis.
- Those on Hydroxycarbamide were reviewed regularly in the nurse led clinics.
- Some had shared care with the SHT based at the Royal London Hospital which worked well, especially if they needed other specialist care and could attend the SHT and speciality joint clinics.

### **Emergency Department and Ward Care**

- The pathway if they were unwell was usually via the ED especially when the MDU was closed.
- Previously they had been able to contact the team and attend the medical day unit for assessment but this was not always possible and they thought the day unit was now only for those attending for aRCE and transfusions.
- There were mixed views about the ED with some saying that care had improved whilst others did not consider care had. Access to timely analgesia was variable and most had lengthy waits and often had to ask for analgesia.
- Concerns were raised by service users that staff in the ED would automatically assume their attendance was due to a vaso-occlusive crisis which had not always been the case, and they did not consider that they had

been appropriately cared for. They felt that their condition had deteriorated before an appropriate diagnosis was made, with one patient commenting that they had then required emergency surgery.

- They did not find the environment in ED pleasant. Following their feedback to the Trust there was now access to a 'soft' chair, although many found sitting for prolonged periods very uncomfortable.
- Patients were all aware that they could attend the ED or MDU three times for one acute episode but would then have to be admitted. They were aware that the pathway had been implemented to manage those who may attend multiple times in a short timeframe but asked whether there could be some flexibility in the number of times they could attend the MDU or ED in one week if they rarely accessed the service
- They commented that the environment on the wards was not pleasant and the wards were dirty and they were concerned about this.
- Those who had experience of being admitted to surgical wards considered that their care was poor and were concerned that if the haematology team had not been available to review them they would have struggled. They considered that the staff on the surgical wards did not sufficient knowledge of their condition and some staff didn't know how to operate a PCA. 'Thankfully the pain team were also on site to support'.
- Comments were made that they had experienced clinical bias, racial inequity, poor behaviours and attitude from some ED and inpatient staff. Many commented about staff making 'snide remarks' which they considered were 'unprofessional and causes more distress to people who are experiencing high levels of pain and distress'.

#### **Day Care, Cannulation and Transfusion Experience**

- Those who attended the MDU for aRCE or transfusions commented that the MDU staff were really 'nice'.
- They thought that when attending the MDU when they were unwell they could not now have the same level of other treatments as before, which resulted in them requiring an inpatient admission.
- Nurse prescribing was in place so they could receive some medications. If a nurse prescriber was not available then they would have lengthy waits for a member of the medical team to attend.
- Most staff were competent in complex cannulation and they did not experience any issues.
- They could experience delays in starting their transfusions which would result in an extended stay on the MDU, or the delivery of their transfusion was accelerated. Some were concerned at the effect this may have on their health if their blood was delivered too quickly, especially those who would then experience a transfusion reaction.
- Access to food when attending the MDU was limited with less options – 'you get a sandwich if you are lucky.'

#### **Feedback**

- Most were aware of the process for feedback and how to make a complaint.
- For the last year representatives from the group also met every three months with the Chief Nurse and representatives from the MDU and SHT to discuss issues. Topics that had been discussed included: -
  - Poor performance with the NICE guidance on pain relief and they had been told that the Trust were working to improve compliance.
  - The number of complaints received which they had been told had reduced, although those who met with the visiting team were sceptical that this was a valid marker of the trust services as many said they no longer bothered to complain about their poor care as 'it makes no difference'.

## Support Groups

- An active support group was in operation 'Solace'. Communication was via a WhatsApp group and regular meetings were held with the option to attend in person or via a video link.

## Other Comments

- There had been funding so they could access complementary therapies when attending but this had now been scaled back.
- Access to 'hot packs' had been replaced with microwavable 'beanies' which they did not consider worked as well.

## Good Practice

1. The feedback from patients and staff who met with the visiting team was overwhelming in their praise of the SHT senior nurses. Patients who met with the visiting team in particular praised the Nurse Consultant, ANP and the CNS team as being 'excellent' in the support they received, commenting that they provided 'personalised care and would listen', problem solve and help with coordinating their care, especially when they were admitted under the care of other speciality teams.
2. Impressive was that senior nursing staff based within the Integrated Acute and Community service rotated across multiple sites, which enabled staff to have a diverse skill set and ensured seamless integration between inpatient and community services. This approach had enabled the service to deliver a comprehensive, patient-centred model of care. Its success had set a strong precedent, inspiring other services to adopt and replicate similar strategies within their own practice.
3. Links with the senior staff in the ED were very good. ED staff would liaise with the SHT about patients who had attended the ED and staff from the ED actively participated at the haemoglobinopathy multidisciplinary team meetings.
4. The SHT in collaboration with the ITU had developed a manual exchange pathway for patients requiring treatment out of hours. The success of the pathway had resulted in the ITU leading on emergency manual exchange across the whole network.
5. Day unit staff had undergone training to enable them to perform midline insertions for patients on the elective aRCE programme.
6. Reviewers were impressed that the SHT had been able to continue to deliver a wide range of training and education for trust staff to raise awareness about, and the care for those living with haemoglobin disorders. The revised RCN competence framework for the care of people with haemoglobin disorders had been implemented for staff in key areas and processes were in place for their competences to be assessed and ongoing monitoring.
7. All patient care protocols had been uploaded on the UCP platform which would enable staff working in primary care and other clinical services to access patients pain management plans.
8. The MDU and ED nursing teams had been piloting Patient Group Directions (PGDs) to initiate some medications and analgesia promptly following assessment. In the ED all experienced Band 5 nurses and above and in the MDU all Band 6 nurses and above had been trained to deliver the PGDs. This initiative aimed to enhance the patient pathway, reduce the time to effective pain relief and improve the overall patient experience. Patients who met with the visiting team valued this initiative.
9. A therapeutic plasma exchange protocol and pathway had been established and implemented at the trust and following positive evaluation and success of the pathway, the team reported that they were actively sharing the pathway and protocol at a range of international platforms.

10. Despite the challenges over the last few years, the service had continued to maintain progress with reducing inpatient length of stays with the use of the 'three time' admission protocol in combination with high intensity users, an increase in the use of aRCE and hydroxycarbamide treatments.
11. The SHT had a supportive management team who recognised the risks that were being experienced and were working to reduce the pressure on the SHT.
12. The SHT had worked hard to demonstrate that they were an appropriate training environment for doctors in training and had been successful in the reinstatement with a Speciality Registrar (StR) due to start a placement in August 2025.
13. The Chief Nurse and representatives from the SHT held meetings with representatives of the Solace patient group every three months. The meetings had been operational for a year and provided a good forum for two way discussion and sharing of information about the haemoglobinopathy service.

## Immediate Risk

### 1. Sustainability of the Specialist Haemoglobinopathy Team <sup>4</sup>

Despite the actions taken by the Trust to maintain the Specialist Haemoglobinopathy Team (SHT) service provided by the Trust, reviewers were extremely concerned about the continued fragility and vulnerability of the haemoglobinopathy service, and the culmination of issues that were impacting on the clinical safety and clinical outcomes of adults and young people with haemoglobin disorders cared for by the trust at the time of the visit for the following reasons: -

- a. There were insufficient consultant staff with specialist experience in the care of adults and young people with haemoglobin disorders on site to provide scheduled and emergency care for the 444 patients under the care of Homerton.
  - i. The Trust had three unfilled substantive consultant haematologist posts.
  - ii. The SHT had an interim Lead Consultant who had four programme activities (PAs) for all haemoglobinopathy work with little time for leadership of the SHT.
  - iii. Two locum consultant haematologists had a total of three PAs allocated for haemoglobinopathy work, however one of the locum consultants was leaving to take up a substantive post.
  - iv. A service level agreement, which had commenced in April 2025, with Barts Health NHS Trust to provide three PAs of Consultant Haematologist time for specialist haemoglobinopathy work (clinics and MDTs) was a temporary arrangement for 18 months and would not be a sustainable option for the future. Barts Health is also experiencing challenges around consultant staffing meaning there is pressure across the entire North East London sector in this respect.
  - v. In total this only amounted to 10 PAs of consultant haemoglobinopathy time for the SHT. This is below the recommended number.
- a. Temporary arrangements for additional out of hours specialist advice and support were also in place provided by Barts Health NHS Trust and Barking, Havering and Redbridge NHS Trust.
- b. The SHT service was closed to new patient referrals and the provision of specialist care to their three linked Local Haemoglobinopathy Teams (LHT) had been suspended with all activity being diverted to the SHT at Barts Health. This had resulted in young people within the City and Hackney area being unable to transition to their nearest adult service and access the provisions of the SHT. Prior to this the SHT had

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<sup>4</sup> [See Trust wide section for Trust and UKFHD Responses](#)

seen a 9-10% increase per year in patient numbers and increasing complexity and acuity of this patient group.

- c. An Advanced Nurse Practitioner had been appointed to support all clinical activity, but utilising the existing consultant haematologist funding, which will potentially impact on the available funding for the consultant haematologist workforce in the future
- d. Much of the oversight and governance of the SHT was dependant on the Nurse Consultant in addition to the clinical aspects of their role. The SHT also had a highly dedicated and expert senior nursing team who, due to the medical workforce shortages, were overstretched taking on additional coordination of patient care and undertaking non role appropriate work. Reviewers were concerned at the ongoing pressure the senior nursing team were experiencing.
- e. The SHT had no data support for audit or data submissions to the NHR or NHSE Specialised Services Quality Dashboard (SSQD). Reviewers were told that data to the SSQD had not been submitted for two years despite requests from NHSE. Completion of the SSQD is a requirement within the NHSE SHT specification as submission provides assurance on the quality of care and patient outcomes by commissioners. The potential impact of non-submission could impact on continued SHT funding and recognition as a specialist haemoglobinopathy team.
- f. The risk to adults had been identified and documented on the Trust risk register, however from discussions with the representative from the specialist services team at North East London ICB this had not been highlighted with them, possibly as the main trust links were with the contracts team at the NEL ICB.
- g. The SHT were not part of the Pan London Sickle Improvement Project meetings and therefore had missed opportunities for additional funding.

As part of discussions about the serious issues faced by the SHT during the visit, reviewers were asked to identify any actions which could be implemented which would optimise the clinical time available, reduce the stress being experienced by the senior nursing team and provide more quality assurance and improved governance: -

- Access to a specific data manager to assist with data collection and entry as well as undertaking specific quality assurance audits would allow the senior nurses to focus on clinical care and service development and ensure appropriate quality assurance reporting.
- Increasing the specific service management capacity dedicated to the haemoglobinopathy service could also relieve the senior nurses of some of their non-clinical responsibilities.

## Serious Concerns

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

## Concern

### 1. SHT Senior Nursing Workload

Reviewers were concerned about the workload of the Nurse Consultant, ANP and CNSs who were working in extenuating circumstances and working well above their contracted hours to ensure patient safety and wellbeing was maintained. The Nurse Consultant was also contacted when not at work and on leave.

Reviewers were made aware that arrangements had been made for staff on the day unit to choose either to claim or take the additional hours as time owing whereas, the SHT senior nurses had not been offered this option or given the current situation they would be unlikely to be able to take time back in lieu due to their clinical commitments and workload.

Reviewers were concerned that the workload they were experiencing was as a direct result of the shortfall in the medical workforce, and if not addressed the senior nurses were at risk of 'burn out' and vulnerable to absences which could potentially impact on staff retention and service viability.

## 2. **Access to Psychology**

At the time of the visit there was 0.4WTE psychotherapist in post who had limited time available to care for the 444 patients under the care of the SHT. The psychotherapist was based in the MDU and due to capacity was unable to see inpatients or patients in the community. The service had waiting list of approximately 20 patients with a waiting time to be seen of about a year. From discussions with staff during the day the pathway for accessing neuropsychology was also unclear.

Reviewers were told 0.4WTE Psychologist had been appointed and was due to start after the visit but this would still not provide sufficient access to psychology based on the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation one WTE clinical health Psychologist for 300 patients.

Reviewers were concerned as without access to sufficient psychology individuals affected by these disorders will have limited specialised psychological input, which may result in increased stress, anxiety, depression, or difficulties in coping with challenges associated with their condition. *See also further consideration section of the report.*

## 3. **Transition**

Prior to reinstatement of transition of young people to the adult SHT at the Trust, work will be required on re-establishing a transition pathway, information for young people and transition guidance specifically covering those transitioning with a haemoglobin disorder. The SHT will also need to ensure there is sufficient staffing in the adult and paediatric teams to provide appropriate support and facilitation to enable the safe transitioning of young people.

## 4. **Guidelines and patient information**

Many of the recommended guidelines were in draft form or out of date. Reviewers were told that the SHT were in the process of updating guidance and patient information but progress was hampered by the lack of clinician time to develop and progress this area of work. Reviewers were concerned that the lack of up to date guidance has the potential to create variations in patient care and potentially outcomes for patients.

## 5. **Resident Doctors Support**

Appropriate supervision and support of doctors in training to sustain the level of junior doctor posts will be important as this would enable the SHT to optimise the remote cover available from the Consultant Haematologists from Barts Health NHS Trust and the Homerton team.

## 6. **High Non-attendance Rates at Clinics**

The SHT were experiencing a high non-attendance rate (DNA) of patients attending outpatient clinics despite patients being contacted on the day of their appointment by the CNSs. Further work on understanding the reasons for non-attendance may be helpful and it may be beneficial to develop a more robust 'hard to reach' strategy that harnesses existing positive engagement, building trust amongst patients via the support group and other established communication channels specifically targeting less engaged patients.

## Further Consideration

1. Patient feedback was insightful about care at the trust and it will be important for the trust to take account of the positive patient views but also act on and build confidence with this patient group around the areas that are causing them concern.
2. The number of patients on Hydroxycarbamide was only 17% which was low for the number of patients cared for by the SHT. The SHT were aware of this and recognised that further work would be required with those eligible about the health benefits associated with the treatment as patients taking hydroxycarbamide are likely to have fewer painful crises, chest crises and blood transfusions.
3. It will be important when your new psychologist is in post, that the service has time to review the service provision to optimise the time available, consider any specific training needs required, and the future needs of the service, taking into account when the service is open to the transition of young people, new referrals and support for their linked LHTs.

## Commissioning

The review team had discussions with specialist services representatives from the regional NHS England London and North East London ICB. Several issues in this report will require the active involvement of the Trust leadership team and commissioners to ensure timely progress is made.

## Appendix 1 Membership of Visiting Team

Visiting Team		
Marie Copple	HCC Haemoglobinopathy Lead Nurse	University Hospitals of Leicester NHS Trust
Heather Rawle	Consultant Clinical and Health Psychologist	Guys and St Thomas NHS Foundation Trust
Kevin Peters	Senior Service Specialist	NHS England
Maureen Scarlett	Community Nurse Specialist	Cambridgeshire Community Services
Dale Seviar	Consultant Haematologist	Guys and St Thomas NHS Foundation Trust
Rajpal Singh	User Representative – Thalassaemia	
Shari Spencer	User Representative – Sickle Cell Disorders	

Clinical Lead		
Emma Drašar	Consultant Haematologist	Whittington Health NHS Trust

NHS Midlands and Lancashire		
Sarah Broomhead	Professional Lead	NHS Midlands and Lancashire

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## Appendix 2 – Compliance with the Quality Standards

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

### Percentage of Quality Standards Met

Service	Number of Applicable QS	Number of QS met	% Met
Specialist Haemoglobinopathy Team (SHT) Adults	45	16	39

## Quality Standards – Care of Adults

Ref	Standard	Met Y/N	Reviewer comment
HA-101	<p><b>Haemoglobin Disorder Service Information</b></p> <p>Written information should be offered to patients and their carers, and should be easily available within patient areas, covering at least:</p> <ol style="list-style-type: none"> <li>a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services</li> <li>b. Clinic times and how to change an appointment</li> <li>c. Ward usually admitted to and its visiting times</li> <li>d. Staff of the service</li> <li>e. Community services and their contact numbers</li> <li>f. Relevant national organisations and local support groups</li> <li>g. Where to go in an emergency</li> <li>h. How to:               <ol style="list-style-type: none"> <li>i. Contact the service for help and advice, including out of hours</li> <li>ii. Access social services</li> <li>iii. Access benefits and immigration advice</li> <li>iv. Contact interpreter and advocacy services, Patient Advice and Liaison Service (PALS), spiritual support and Healthwatch (or equivalent)</li> <li>v. Give feedback on the service, including how to make a complaint</li> <li>vi. Get involved in improving services (QS HA-199)</li> </ol> </li> </ol>	N	<p>Some information was available but the team were in the process of updating information and making the information available electronically. At the time of the visit not all the information relating the QS had been finalised.</p>

Ref	Standard	Met Y/N	Reviewer comment
HA-102	<p><b>Information about Haemoglobin Disorders</b></p> <p>Patients and their carers should be offered written information, or written guidance on where to access information, covering at least:</p> <ul style="list-style-type: none"> <li>a. A description of their condition (SCD or Th), how it might affect them and treatment available</li> <li>b. Inheritance of the condition and implications for fertility</li> <li>c. Problems, symptoms and signs for which emergency advice should be sought</li> <li>d. How to manage pain at home (SCD only)</li> <li>e. Transfusion and iron chelation</li> <li>f. Possible complications</li> <li>g. Health promotion, including: <ul style="list-style-type: none"> <li>i. Travel advice</li> <li>ii. Vaccination advice</li> </ul> </li> </ul> <p>National Haemoglobinopathy Registry, its purpose and benefits</p> <p>Self-administration of medications and infusions</p>	Y	
HA-103	<p><b>Care Plan</b></p> <p>All patients should be offered:</p> <ul style="list-style-type: none"> <li>a. An individual care plan or written summary of their annual review including: <ul style="list-style-type: none"> <li>i. Information about their condition</li> <li>ii. Planned acute and long-term management of their condition, including medication</li> <li>iii. Named contact for queries and advice</li> </ul> </li> <li>b. A permanent record of consultations at which changes to their care are discussed</li> </ul> <p>The care plan and details of any changes should be copied to the patient's GP and their local team consultant (if applicable).</p>	Y	
HA-104	<p><b>What to Do in an Emergency?</b></p> <p>All patients should be offered information about what to do in an emergency covering at least:</p> <ul style="list-style-type: none"> <li>a. Where to go in an emergency</li> <li>b. Pain relief and usual baseline oxygen level, if abnormal (SCD only)</li> </ul>	Y	Patients were aware of what to do in an Emergency. Those living with a Sickle Cell Disorders all had pain protocols

Ref	Standard	Met Y/N	Reviewer comment
HA-105	<p><b>Information for Primary Health Care Team</b></p> <p>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:</p> <ol style="list-style-type: none"> <li>The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD)</li> <li>Side effects of medication, including chelator agents (SCD and Th)</li> <li>Guidance for GPs on: <ol style="list-style-type: none"> <li>Immunisations</li> <li>Contraception and sexual health</li> </ol> </li> <li>What to do in an emergency</li> <li>Indications and arrangements for seeking advice from the specialist service</li> </ol>	N	<p>Reviewers did not see any information relating to side effects of medication and information for GPs for those living with thalassaemia.</p> <p>Information was in place in terms of the City and Hackney Adult Referral Pathway for Sickle Cell Disease (SCD) and Thalassaemia; City and Hackney paediatric (0-16 year olds) acute sickle cell illness pathway, Preconception Clinics and Obstetric Medical Clinics</p>
HA-194	<p><b>Environment and Facilities</b></p> <p>The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders.</p>	Y	
HA-195	<p><b>Transition to Adult Services</b></p> <p>Young people approaching the time when their care will transfer to adult services should be offered:</p> <ol style="list-style-type: none"> <li>Information and support on taking responsibility for their own care</li> <li>The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services</li> <li>A named coordinator for the transfer of care</li> <li>A preparation period prior to transfer</li> <li>Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care</li> <li>Advice for young people leaving home or studying away from home including: <ol style="list-style-type: none"> <li>Registering with a GP</li> <li>How to access emergency and routine care</li> <li>How to access support from their specialist service</li> <li>Communication with their new GP</li> </ol> </li> </ol>	N/A	The transition of young people to the adult SHT at HH had been suspended.
HA-197	<p><b>Gathering Patients' and Carers' Views</b></p> <p>The service should gather patients' and carers' views at least every three years using:</p> <ol style="list-style-type: none"> <li>'Patient Survey for Adults with a Sickle Cell Disorder'</li> <li>UKTS Survey for Adults living with Thalassaemia</li> </ol>	N	Patient surveys as per the QS had not been undertaken.

Ref	Standard	Met Y/N	Reviewer comment
HA-199	<p><b>Involving Patients and Carers</b></p> <p>The service's involvement of patients and carers should include:</p> <ol style="list-style-type: none"> <li>a. Mechanisms for receiving feedback</li> <li>b. Mechanisms for involving patients and their carers in: <ol style="list-style-type: none"> <li>i. Decisions about the organisation of the service</li> <li>ii. Discussion of patient experience and clinical outcomes (QS HA-797)</li> <li>iii. Examples of changes made as a result of feedback and involvement</li> </ol> </li> </ol>	Y	<p>The 'Solace SG' patient group was active for those living with sickle cell and thalassaemia living in the City and Hackney area.</p> <p>Patients who met with the visiting team had been involved in discussions around patient feedback and changes had been made as a result.</p>
HA-201	<p><b>Lead Consultant</b></p> <p>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.</p>	N	<p>The interim Lead Consultant did not have time for leadership of the SHT.</p>
HA-202	<p><b>Lead Nurse</b></p> <p>A lead nurse should be available with:</p> <ol style="list-style-type: none"> <li>a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders</li> <li>b. Responsibility for liaison with other services</li> <li>c. Competences in caring for people with haemoglobin disorders</li> </ol> <p>The lead nurse should have appropriate time for their leadership role and cover for absences should be available.</p>	Y	<p>The Nurse Consultant was the designated Lead Nurse for the SHT (1 WTE).</p> <p>Cover for absences was from the CNS team.</p>
HA-204	<p><b>Medical Staffing and Competences: Clinics and Regular Reviews</b></p> <p>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.</p> <p>Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.</p>	N	<p>The SHT had only a total of 10 PAs for the care of 444 patients with red cell disorders including the three PAs from Barts Health NHS Trust to undertake clinics on the HH site.</p> <p>The Trust had three consultant haematologist vacancies covered by two locums one of whom was about the leave for a substantive post.</p>

Ref	Standard	Met Y/N	Reviewer comment
HA-205	<p><b>Medical Staffing and Competences: Unscheduled Care</b></p> <p>24/7 consultant and junior staffing for unscheduled care should be available.</p> <p>SHTs and HCCs only:</p> <p>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.</p>	Y	<p>Onsite on call haematology consultant available Mon-Fri 9am-5pm. Out of hours arrangements were in place for offsite haematology consultant advice from RLH and BHR.</p> <p>Haematology resident doctors in training were available Mon to Fri 9am to 5pm, outside of these hours patients were seen by the acute medical team resident doctors in training.</p>
HA-206	<p><b>Doctors in Training</b></p> <p>If doctors in training are part of achieving Qs 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.</p>	N/A	<p>At the time of the visit there were no doctors in training allocated to the service but the SHT would have a Specialty Registrar from August 2025.</p> <p>The SHT reported that when allocated they do have the opportunity to gain competences in all aspects of haemoglobinopathies</p>
HA-207	<p><b>Nurse Staffing and Competences</b></p> <p>The service should have sufficient nursing staff with appropriate competences in the care of people with haemoglobin disorders, including:</p> <ol style="list-style-type: none"> <li>Clinical nurse specialist(s) with responsibility for the acute service</li> <li>Clinical nurse specialist(s) with responsibility for the community service</li> <li>Ward-based nursing staff</li> <li>Day unit (or equivalent) nursing staff</li> <li>Nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion.</li> </ol> <p>Staffing levels should be appropriate for the number of patients cared for by the service and its role.</p> <p>Cover for absences should be available.</p>	N	<p>Nurse Consultant 1WTE and CNS (4WTE) for adults covered the acute and community service as well as coordinating the service and non-role activities.</p> <p>A comprehensive range of competence based training was in place and delivered by the SHT.</p>

Ref	Standard	Met Y/N	Reviewer comment
HA-208	<p><b>Psychology Staffing and Competences</b></p> <p>The service should have sufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders, including:</p> <ol style="list-style-type: none"> <li>An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care</li> <li>Time for input to the service's multidisciplinary discussions and governance activities</li> <li>Provision of, or arrangements for liaison with and referral to, neuropsychology</li> </ol> <p>Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.</p>	N	<p>The SHT only had 0.8WTE available for psychotherapy and psychology for 444 people living with haemoglobin disorders. At the time of the visit the psychology post (0.4WTE) was vacant with a new post holder due to commence shortly after the visit. The Psychotherapist (0.4WTE) was only able to see a limited number of patients.</p> <p>There was no cover for absences. The pathway for those needing neuropsychology was not clear with staff assuming there was a pathway.</p>
HA-299	<p><b>Administrative, Clerical and Data Collection Support</b></p> <p>Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.</p>	N	<p>The SHT had no support for data. <i>See main report</i></p>
HA-301	<p><b>Support Services</b></p> <p>Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HA-602) as required:</p> <ol style="list-style-type: none"> <li>Social worker / benefits adviser</li> <li>Leg ulcer service</li> <li>Dietetics</li> <li>Physiotherapy (inpatient and community-based)</li> <li>Occupational therapy</li> <li>Mental health services</li> </ol>	Y	
HA-302	<p><b>Specialist Support</b></p> <p>Access to the following specialist staff and services should be easily available:</p> <ol style="list-style-type: none"> <li>DNA studies</li> <li>Genetic counselling</li> <li>Sleep studies</li> <li>Diagnostic radiology</li> <li>Manual exchange transfusion (24/7)</li> <li>Automated red cell exchange transfusion (24/7)</li> <li>Pain team including specialist monitoring of patients with complex analgesia needs</li> <li>Level 2 and 3 critical care</li> </ol>	N	<p>aRCE was only available Monday to Friday 9am to 5 pm. All other specialist support was available.</p>

Ref	Standard	Met Y/N	Reviewer comment
HA-303	<p><b>Laboratory Services</b></p> <p>UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.</p>	Y	NHS East and South East London Pathology Partnership
HA-304	<p><b>Urgent Care – Staff Competences</b></p> <p>Medical and nursing staff working in Emergency Departments and admission units should have competences in urgent care of people with haemoglobin disorders.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. <i>This QS applies to Emergency Departments, Medical Admissions Units and any other areas to which people with haemoglobin disorders are normally admitted.</i></li> <li>2. <i>Documentation of training undertaken and discussion of audits of compliance with NICE Clinical Guideline on the management of acute pain could be used to demonstrate compliance with this QS.</i></li> </ol>	Y	A regular haemoglobinopathy competence based training programme for ED staff was in place. An audit of the NICE guidance on the timeliness of analgesia was in progress. Initial results were reported to reviewers to have seen an increase in compliance of about 50%.
HA-501	<p><b>Transition Guidelines</b></p> <p>Guidelines on transition to adult care should be in use covering at least:</p> <ol style="list-style-type: none"> <li>a. Age guidelines for timing of the transfer</li> <li>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</li> <li>c. Allocation of a named coordinator for the transfer of care</li> <li>d. A preparation period and education programme relating to transfer to adult care</li> <li>e. Communication of clinical information from paediatric to adult services</li> <li>f. Arrangements for monitoring during the time immediately after transfer to adult care</li> <li>g. Arrangements for communication between HCCs, SHTs and LHTs (if applicable)</li> <li>h. Responsibilities for giving information to the young person and their family or carer (QS HA-195)</li> </ol>	N/A	<p>Transition of young people to the SHT at HH had been suspended, however, the Trust wide transition guidance based on the national ‘ready, steady, go, hello’ principles did not seem to cover the arrival in adult services ‘Hello.’ The trust wide guidance also covered some conditions but not young people with haemoglobinopathies.</p> <p><i>See also main report</i></p>

Ref	Standard	Met Y/N	Reviewer comment
HA-502	<p><b>New Patient and Annual Review Guidelines</b> Guidelines or templates should be in use covering:</p> <ul style="list-style-type: none"> <li>a. First outpatient appointment</li> <li>b. Annual review</li> </ul> <p>Guidelines should cover both clinical practice and information for patients and carers.</p>	N	Outpatient guidance and SOP seen, however the information was not clear for new patients. The documentation seen was not version controlled.
HA-505	<p><b>Transfusion Guidelines</b> Transfusion guidelines should be in use covering:</p> <ul style="list-style-type: none"> <li>a. Indications for: <ul style="list-style-type: none"> <li>i. Emergency and regular transfusion</li> <li>ii. Use of simple or exchange transfusion</li> <li>iii. Offering access to automated exchange transfusion to patients on long-term transfusions</li> </ul> </li> <li>b. Protocol for: <ul style="list-style-type: none"> <li>i. Manual exchange transfusion</li> <li>ii. Automated exchange transfusion on site or organised by another provider</li> </ul> </li> <li>c. Investigations and vaccinations prior to first transfusion</li> <li>d. Recommended number of cannulation attempts</li> <li>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</li> <li>f. Patient pathway for Central Venous Access Device insertion, management and removal</li> </ul>	N	<p>The trust wide transfusion policy did not mention SCD or Thalassaemia. There was no guidance covering phenotypes and no SOP covering aRCE.</p> <p>Guidance was in place covering plasma exchange, manual exchange, and cannulation.</p>
HA-506	<p><b>Chelation Therapy</b> Guidelines on chelation therapy should be in use covering:</p> <ul style="list-style-type: none"> <li>a. Indications for chelation therapy</li> <li>b. Choice of chelation drug(s), dosage and dosage adjustment</li> <li>c. Monitoring of haemoglobin levels prior to transfusion</li> <li>d. Management and monitoring of iron overload, including management of chelator side effects</li> <li>e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2</li> <li>f. Self-administration of medications and infusions and encouraging patient and carer involvement in monitoring wherever possible</li> </ul>	N	The guidelines were out of date but did meet the requirements of the QS.

Ref	Standard	Met Y/N	Reviewer comment
HA-507	<p><b>Hydroxycarbamide and Other Disease Modifying Therapies</b></p> <p>Guidelines on hydroxycarbamide and other disease modifying therapies should be in use covering:</p> <ol style="list-style-type: none"> <li>Indications for initiation</li> <li>Monitoring of compliance and clinical response, including achieving maximum tolerated dose for hydroxycarbamide</li> <li>Documenting reasons for non-compliance</li> <li>Monitoring of complications</li> <li>Indications for discontinuation</li> </ol>	N	The shared care guidance was out of date.
HA-508	<p><b>Non-Transfusion Dependent Thalassaemia (nTDT)</b></p> <p>Guidelines on the management of Non-Transfusion Dependent Thalassaemia should be in use, covering:</p> <ol style="list-style-type: none"> <li>Indications for transfusion</li> <li>Monitoring iron loading</li> <li>Indications for splenectomy</li> <li>Consideration of options for disease modifying therapy</li> </ol>	N	The guidelines were out of date but did meet the requirements of the QS.
HA-509	<p><b>Clinical Guidelines: Acute Complications</b></p> <p>Guidelines on the management of the acute complications listed below should be in use covering at least:</p> <ol style="list-style-type: none"> <li>Local management</li> <li>Indications for seeking advice from the HCC/SHT</li> <li>Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred</li> </ol> <p>For patients with sickle cell disorder:</p> <ol style="list-style-type: none"> <li>Acute pain</li> <li>Fever, infection and overwhelming sepsis</li> <li>Acute chest syndrome</li> <li>Abdominal pain and jaundice</li> <li>Acute anaemia</li> <li>Stroke and other acute neurological events</li> <li>Priapism</li> <li>Acute renal failure</li> <li>Haematuria</li> <li>Acute changes in vision</li> </ol> <p>For patients with thalassaemia:</p> <ol style="list-style-type: none"> <li>Fever, infection and overwhelming sepsis</li> <li>Cardiac, hepatic or endocrine decompensation</li> </ol>	N	<p>The guidelines did not cover 'h' or 'l'. All other aspects were met</p> <p>The Thalassaemia guidance expired in March 2025 but did meet the requirements of the QS.</p>

Ref	Standard	Met Y/N	Reviewer comment
HA-510	<p><b>Clinical Guidelines: Chronic Complications</b></p> <p>Guidelines on the management of the chronic complications listed below should be in use covering at least:</p> <ul style="list-style-type: none"> <li>i. Local management</li> <li>ii. Indications for discussion at the HCC MDT</li> <li>iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred</li> <li>iv. Arrangements for specialist multidisciplinary review</li> </ul> <ul style="list-style-type: none"> <li>a. Renal disease, including sickle nephropathy</li> <li>b. Orthopaedic problems, including the management of sickle and thalassaemia-related bone disease</li> <li>c. Eye problems, including sickle retinopathy and chelation-related eye disease</li> <li>d. Cardiological complications, including sickle cardiomyopathy and iron overload related heart disease</li> <li>e. Pulmonary hypertension</li> <li>f. Chronic respiratory disease, including sickle lung disease and obstructive sleep apnoea</li> <li>g. Endocrine problems, including endocrinopathies and osteoporosis</li> <li>h. Neurological complications, including sickle vasculopathy, other complications requiring neurology or neurosurgical input and access to interventional and neuroradiology</li> <li>i. Chronic pain</li> <li>j. Hepatobiliary disease, including sickle hepatopathy, viral liver disease and iron overload-related liver disease</li> <li>k. Urological complications, including priapism and erectile dysfunction</li> <li>l. Dental problems</li> </ul>	N	The guidance available did not cover all the chronic complications as defined in the QS.
HA-511	<p><b>Anaesthesia and Surgery</b></p> <p>Guidelines should be in use covering the care of patients with sickle cell disorder and thalassaemia during anaesthesia and surgery.</p>	N	There were no guidelines covering the care of patients with Sickle Cell Disorders and Thalassaemia during anaesthesia and surgery.

Ref	Standard	Met Y/N	Reviewer comment
HA-512	<p><b>Fertility and Pregnancy</b></p> <p>Guidelines should be in use covering:</p> <ul style="list-style-type: none"> <li>a. Fertility, including fertility preservation, assisted conception and pre-implantation genetic diagnosis</li> <li>b. Care during pregnancy and delivery</li> <li>c. Post-partum care of the mother and baby</li> </ul> <p>Guidelines should cover:</p> <ul style="list-style-type: none"> <li>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</li> <li>ii. Arrangements for access to anaesthetists with an interest in the management of high-risk pregnancy and delivery</li> <li>iii. Arrangements for access to special care or neonatal intensive care, if required</li> <li>iv. Indications for discussion at the HCC MDT (QS HA-605)</li> <li>v. Arrangements for care of pregnant young women aged under 18</li> </ul>	Y	
HA-599	<p><b>Clinical Guideline Availability</b></p> <p>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.</p>	Y	

Ref	Standard	Met Y/N	Reviewer comment
HA-601	<p><b>Service Organisation</b></p> <p>A service organisation policy should be in use covering arrangements for:</p> <ol style="list-style-type: none"> <li>Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission</li> <li>Patient discussion at local multidisciplinary team meetings (QS HA-604)</li> <li>Follow up of patients who 'did not attend'</li> <li>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</li> <li>If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together</li> <li>Governance arrangements for providing consultations, assessments and therapeutic interventions virtually, in the home or in informal locations</li> </ol>	N	An operational document was in place but was out of date and did not reflect current practice.
HA-603	<p><b>Shared Care Agreement with LHTs</b></p> <p>A written agreement should be in place with each LHT covering:</p> <ol style="list-style-type: none"> <li>Whether or not annual reviews are delegated to the LHT</li> <li>New patient and annual review guidelines (QS HA-502) (if annual reviews are delegated)</li> <li>LHT management and referral guidelines (QS HA-503)</li> <li>National Haemoglobinopathy Registry data collection (QS HA-701)</li> <li>Two-way communication of patient information between HCC/SHT and LHT</li> <li>Attendance at HCC business meetings (HA-607) (if applicable)</li> <li>Participation in HCC-agreed audits (HA-706)</li> </ol>	N	There were no shared care agreements in place covering the existing patients who were receiving their specialist care from the SHT from the LHTs.
HA-604	<p><b>Local Multidisciplinary Meetings</b></p> <p>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).</p>	Y	

Ref	Standard	Met Y/N	Reviewer comment
HA-606	<p><b>Service Level Agreement with Community Services</b></p> <p>A service level agreement for support from community services should be in place covering, at least:</p> <ol style="list-style-type: none"> <li>Role of community service in the care of patients with haemoglobin disorders</li> <li>Two-way exchange of information between hospital and community services.</li> </ol>	N/A	Integrated Trust
HA-607 S	<p><b>HCC Business Meeting Attendance (SCD)</b></p> <p>At least one representative of the team should attend each HCC Business Meeting (QS HA-702).</p>	Y	
HA-607 T	<p><b>HCC Business Meeting Attendance (Th)</b></p> <p>At least one representative of the team should attend each HCC Business Meeting (QS HA-702).</p>	N	Representation at the HCC meetings had only been possible for one out of the last three meetings held
HA-701	<p><b>National Haemoglobinopathy Registry</b></p> <p>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.</p>	N	Not all data was submitted to NHR as submission was reliant on clinical staff. Reviewers were told that data were collected but not uploaded.
HA-705	<p><b>Other Audits</b></p> <p>Clinical audits covering the following areas should have been undertaken within the last two years:</p> <ol style="list-style-type: none"> <li>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)</li> <li>Acute admissions to inappropriate settings, including patient and clinical feedback on these admissions</li> </ol>	N	Audits as defined in the QS had not been undertaken due to the lack of time and data support.
HA-706	<p><b>HCC Audits</b></p> <p>The service should participate in agreed HCC-specified audits (QS H-702d).</p>	N	The SHT had not had time and resource to participate with the HCC audits.
HA-707	<p><b>Research</b></p> <p>The service should actively participate in HCC-agreed research trials.</p>	Y	

Ref	Standard	Met Y/N	Reviewer comment
HA-797	<p><b>Review of Patient Experience and Clinical Outcomes</b></p> <p>The service's multidisciplinary team, with patient and carer representatives, should review at least annually:</p> <ul style="list-style-type: none"> <li>a. Achievement of Quality Dashboard metrics compared with other services</li> <li>b. Achievement of Patient Survey results (QS HA-197) compared with other services</li> <li>c. Results of audits (QS HA-705): <ul style="list-style-type: none"> <li>i. Timescales and pathway for regular transfusions</li> <li>ii. Patients admitted to inappropriate settings</li> </ul> </li> </ul> <p>Where necessary, actions to improve access, patient experience and clinical outcomes should be agreed. Implementation of these actions should be monitored.</p>	N	This QS could not be met as the patient survey results and comparisons with other services 'a' and the audits for 'b' and 'c' had not been completed.
HA-798	<p><b>Review and Learning</b></p> <p>The service should have appropriate multidisciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, serious adverse events, incidents and 'near misses'.</p>	Y	
HA-799	<p><b>Document Control</b></p> <p>All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.</p>	N	The team were in the process of updating guidance. At the time of the visit many guidelines were out of date.

## Appendix 3 Immediate Risk Actions

### Trust and UKFHD Steering Group Responses

#### Trust Response received 26<sup>th</sup> June 2025:

Thank you and the UKFHD panel members for dedicating your time to review the health services for people with Haemoglobin disorders at Homerton Healthcare NHS Foundation Trust on 18th June 2025. We acknowledge the concerns raised in your letter and offer the following initial response within the timeframe provided. We will continue to address any necessary measures as part of our ongoing action plan through Divisional structures and in collaboration with the team.

We fully recognise and accept the very challenging circumstances in which the Haematology team have been working, particularly over the past year and a half. Despite these pressures, the team has maintained a high standard of patient care, often at the expense of their own health and wellbeing - a situation we acknowledge cannot be sustained. The Division remains committed to advocating for staff wellbeing, ensuring all team members are aware of the support available through the Trust's wellbeing resources, including Talking Therapies, Health Assured, staff networks, occupational health, and external support options. We will also provide protected time for staff who wish to access these services.

In response to the issues identified in your review, the Division is initiating a comprehensive review of the Haematology service, including the haemoglobinopathy pathway. This review will consider workforce configuration, administrative and operational support, patient outcomes and experience, and collaborative working within the North East London (NEL) network. The aim is to develop a sustainable and resilient service model, and the findings will directly inform our action plan. This will be shared with the Specialist Services team in July. While financial constraints across the NHS are recognised, the Clinical and Divisional teams remain focused on delivering a safe and effective service for both patients and staff.

There is collective recognition among the wider multidisciplinary team, operational leadership, consultants, and nursing staff that the current model of delivery is no longer fit for purpose. We are committed to working with the network to co-design a revised model. We also acknowledge the similar workforce challenges faced by Barts Health, as referenced in your letter, and believe a collaborative approach across organisations will be key to addressing these issues. While these wider discussions continue, once the gaps in Haemoglobinopathy service provision have been identified through our internal service review, we will explore alternative skill mix options for the consultant vacancy funding alongside the already established joint Consultant post with Barts Health, Nurse Consultant, and Advanced Nursing Practitioner role. As agreed during the visit, we remain open to exploring a range of staffing models, including the use of different medical staff groups and grades, such as Associate Specialists, Specialist Doctors, and GPs with a special interest in red cell disorders to support the development of a sustainable and effective service delivery model. The Divisional and Clinical team will work together to define the optimal delivery model as part of the ongoing service review. This process will include a comprehensive evaluation of all clinical roles, not limited to the Advanced Nurse Practitioner position, in the context of available funding for Consultant Haematologist posts. While decisions regarding the appropriate clinical roles will be clinically led, the overall funding envelope for the service will remain unchanged.

As part of the move towards a collaborative network model, we will also ensure that job planned PA allocations are aligned to support on-call arrangements. In the interim, while recruitment to the joint consultant post with Barts Health remains uncertain, we hope it will help stabilise haemoglobinopathy services and allow a safe resumption of new referrals. Meanwhile, we will continue to explore the broader recruitment and workforce planning options outlined above.

Since the review, we have also commenced discussions with commissioners regarding the potential for additional funding to support a dedicated Data Manager post. This would reduce the administrative burden on the nursing team and improve capacity for clinical care. In the meantime, immediate support requirements have

been reviewed by the operational management team and our Nurse Consultant, alongside discussions with the business intelligence team. Additionally, we are reviewing the Haematology department's budget and the wider Divisional administrative resources to identify opportunities for interim support. The aim is for an administrator to temporarily take on the necessary responsibilities until a funded Data Manager post is secured. The Data Manager will be responsible for coordinating national and local audits related to patient outcomes and experience, as well as overseeing external reporting requirements, including the SSQD submission.

Once the action plan has been developed and reviewed with the clinical teams, we will assess the associated risks and agree on appropriate risk levels. This process will include identifying existing, additional, or alternative risks. We will also commit to meeting with the Specialist Services team at NEL ICB to escalate concerns where necessary and ensure appropriate mitigation strategies are in place. We are equally disappointed to have missed opportunities for funding and development by not being active members of the Pan London Sickle Improvement Project meetings. Thank you for connecting us with the team moving forward, which will be instrumental in supporting the delivery of the action plan we are currently developing. We will ensure staff are released in order to participate now the invitation has been shared.

We are grateful for the panel's time, insight, and continued commitment to improving haemoglobinopathy services. We remain committed to working transparently and constructively with all stakeholders to deliver safe, equitable, and sustainable care for our patients.

**UKFHD Response sent 30<sup>th</sup> June 2025:**

Thank you for the prompt response, recognising the issues raised at the peer review visit and your plan to improve conditions for your staff and patients working collaboratively with your network and commissioners.