

HCC SOUTH EAST LONDON & SOUTH EAST ANNUAL REPORT

2024-2025

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1 Introduction

This annual report covers the period April 1st 2024 to March 31st 2025.

The South East London and South East Haemoglobinopathy Coordinating Centre (SELSE HCC) aims provide high quality specialist care for patients with haemoglobinopathies. We have worked towards addressing concerns raised in our 2024 Peer Review report. We have an expanded research portfolio including the novel therapeutic agents, Mitapivat and Etavopivat, and increased access to cutting edge potentially curative treatments such as reduced intensity fully matched sibling stem cell transplantation, the REDRESS study of haploidentical stem cell transplant in adults, and are preparing our first patients for NHS funded gene therapy.

The reduced intensity Haematopoietic Stem Cell Transplant (HSCT) programme for adults with Sickle Cell Disorders (SCD) started the programme with the first patient conditioning in November 2021 and a total of 19 patients have received transplants, with the procedure being successful in 16, with graft rejection occurring in three individuals. The REDRESS trial of haploidentical stem cell transplants in adults with SCD launched in May 2023, and in our network 14 patients have been randomised and 1 patient has had a successful transplant. The remaining patients were either randomised to best supportive care so were not eligible for a stem cell transplant, or have had their transplant delayed for patient personal reasons.

The All-Party Parliamentary Group (APPG) for sickle cell and thalassemia produced the 'No-one's Listening' report in November 2021, highlighting inadequacies in care for patients with SCD. As a network, we have worked to address issues raised. Significant improvements to the care of those with SCD have been achieved, facilitated by the shared electronic patient record 'Epic' at GSTT, Evelina Children's Hospital and KCH which allows patient access to many aspects of their medical notes, easily updated full and accessible pop up care plans, and automatic real-time flag of all sickle inpatients. We are working to achieve accurate real time audit of time to analgesia for patients presenting to the Emergency Departments of GSTT and KCH, and have completed a whole network audit of time to analgesia which shows improvement compared with last year's audit.

Our in-house co-produced e-learning educational module has been mandated for all patient-facing staff in the Emergency Department, Haematology and Paediatric Departments at Guy's and St. Thomas's hospitals, Evelina Children's Hospital and King's College Hospital, with future rollout to University Hospital Lewisham, Queen Elizabeth Hospital in Woolwich, and Croydon University Hospital planned. The module is being made freely available to any other interested Trusts, with the expectation that this will eventually be compulsory for all Emergency Department, Haematology and Paediatric hospital staff across the network.

The NHS England and IBC funded and co-developed the South East London Enhanced Community Service. This service includes benefits and housing officers; psychologist run online workshops; legal assistance; specialist community nurses to promote community care, education and self-management; peer to peer support facilitated by the Sickle Cell Society; and access to specialist community dietetics, pharmacy and physiotherapy staff. The Enhanced Community Service has been accessed by many of our patients from the six eligible boroughs of Southwark, Lambeth, Bromley, Bexley, Lewisham and Greenwich. Staff are fully recruited and have successfully overcome the challenges of managing safe information sharing across different hospital trusts, are working at 100% capacity and have been nominated for two healthcare awards.

As a network we continue to provide regular network sickle awareness and education to patient groups, staff and nurses and doctors in training, including embedding the NHSE sickle acronym "ACT NOW". We provide regular twice a year specialist registrar haemoglobinopathy teaching, regular nursing training, an online annual patient and career education, and quarterly network staff education sessions.

As a network, we made the decision to fund ASCAT (Academy for Sickle Cell and Thalassaemia) annual conference places for key staff members (adult and paediatric lead consultants, clinical nurse specialists and allied health professionals, as well as an adult patient and parent representatives) from each SHT and LHT within our network. This will result in significant upskilling and invigoration of local and specialist teams, as well as our patient representatives, who are so important to our services and patient support groups.

Many thanks to the staff across the HCC who have contributed to this report and worked so hard during 2024/25.

2 Background

In 2019, King's College Hospital NHS Foundation Trust, Guy's and St Thomas NHS Foundation Trust and the Evelina London Children's Hospital were jointly successful in bidding to host the Haemoglobinopathy Coordinating Centre for South East London and South East (HCC SELSE). Building on the strong foundation of work already completed by the South Thames Sickle Cell Network (STSTN), SELSE HCC is a collaboration of haemoglobinopathy healthcare professionals including Consultants, Nurses, Psychologists and others across the region's network of care settings.

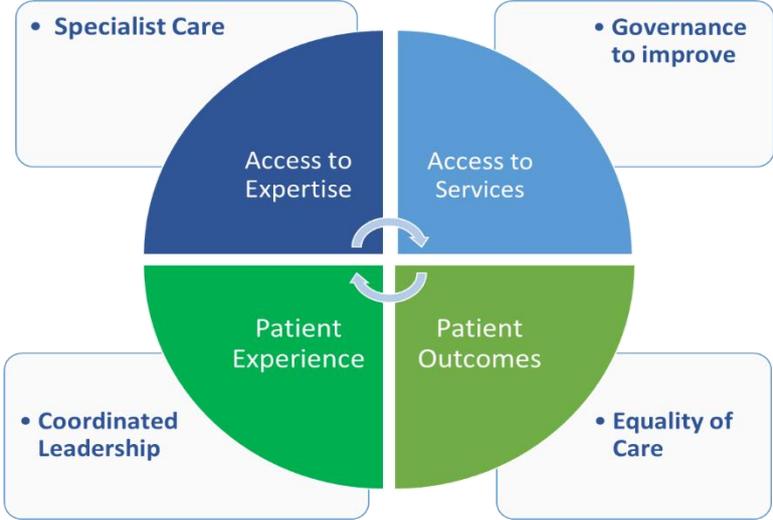
NHS England has contracted the specialised service to deliver specialist and non-specialist haemoglobinopathy services to adults and children and to provide expert opinion and management for complex patients. The central aims of the service are to reduce levels of morbidity and mortality and improve the experience of patients by reducing inequalities and improving timely access to high quality expert care. The HCC is responsible for providing a networked approach to the delivery of haemoglobinopathy services.

Alongside SELSE HCC, King's College Hospital NHS Foundation Trust (KCH), Guy's and St Thomas NHS Foundation Trust (GSTT) and the Evelina London Children's Hospital (ELCH) were also appointed to host the National Haemoglobinopathy Panel (NHP). The NHP provides expert multi-disciplinary advice on the management of complex patients with sickle cell disease, thalassaemia and rare anaemias and on new and emerging treatments in the field of haematology. The NHP has established itself as a national platform, providing a forum to agree and communicate upon matters impacting haemoglobinopathy patients across the country. The contract to host the NHP was re-awarded to SELSE last year and we appointed a new chair, Dr Kate Gardner, Consultant Haematologist at GSTT to lead the panel.

HCC

South East London and South East

HCC SELSE Networked Model of Care

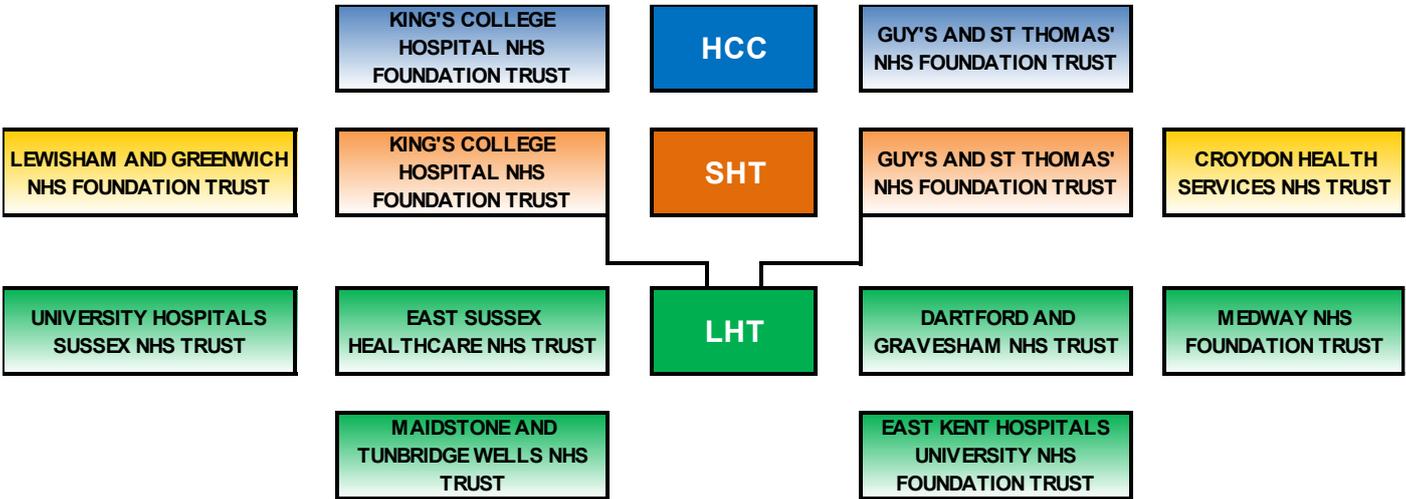


3 HCC Framework

The national framework established ten HCCs for the treatment of Sickle Cell across the country and our HCC SELSE serves a large geographical area stretching across South East London and South East England. Additionally, four HCC collaborations have been created specifically for the management of patients with Thalassaemia and Rare Anaemias and we support our colleagues from HCC East London in the delivery of this, which is led by Barts Health NHS Trust.

The HCC SELSE Trusts (KCH, GSTT, ELCH) provide clinical leadership and professional management, while the network’s Specialist Haemoglobinopathy Teams (SHTs), Lewisham and Greenwich NHS Trust and Croydon Health Services Trust, partnered with King’s and Guy’s, focus on the delivery of care to our patients across inpatient, outpatient and outreach clinical settings. The HCC network is structured so that King’s and Guy’s act as the SHT network partners to our Local Haemoglobinopathy Teams (LHTs) and community care providers, working alongside clinicians in various joint clinics and outreach settings and providing general network support.

The South East London and South East England Haemoglobinopathy Coordinating Centre NHS Trust network is structured as below:



Our HCC trust network creates a care framework that incorporates multiple hospital sites, regional community care settings and our partners in the primary care services. Together, we aim to deliver a comprehensive network of specialised haemoglobinopathy care to our patient population across South East London and South East England.

Network Role	Name	Hospital base
Lead	Dr Sara Stuart-Smith	King's College Hospital (KCH)
Deputy Lead	Dr Rachel Kesse-Adu	Guy's and St Thomas' Hospital (GSTT)
Network Manager	Maria Omosore	KCH/GSTT
Network Administrator	Thera Broni	KCH/GSTT
Network Practice Development Nurse	Chifundo Stubbs	KCH/GSTT
Network Data Support	Cheryl Robinson	KCH/GSTT
Outreach Lead	Arne de Kreuk	KCH
Education	Rachel Kesse-Adu/Moji Awogbade	GSTT
MDM	Arne de Kreuk, Nick Fordham	GSTT
Adult Guidelines	Rachel Kesse-Adu/Sara Stuart-Smith/Tullie Yeghen	Lewisham and Greenwich NHS Trust (LGT)
Paediatric Guidelines	Samah Babiker/ John Brewin/ Sarah Wilkinson	GSTT; LGT
Research	David Rees	KCH
Transcranial Doppler	John Brewin	KCH
Data	Kate Gardner/John Brewin	GSTT
Annual Report	John Brewin	KCH
Audit	Samah Babiker	GSTT
Newborn Screening	Subarna Chakravorty	KCH
PREMS	Subarna Chakravorty	KCH
Patient Education	Samah Babiker	GSTT

3.1 Specialist Haemoglobinopathy Teams (SHT)

King's College Hospital NHS Foundation Trust

Adult team:
 Dr Sara Stuart-Smith: sara.stuartsmith@nhs.net
 Dr Moji Awogbade: moji.awogbade@nhs.net
 Dr Arne de Kreuk arne.dekreuk@nhs.net

Paediatric team:
 Prof Rees: david.rees2@nhs.net
 Dr Subarna Chakravorty: subarna.chakravorty@nhs.net
 Dr Sue Height sue.height@nhs.net
 Dr John Brewin: j.brewin@nhs.net

Guy's and St Thomas' Hospital NHS Foundation Trust and Evelina Children's Hospital

Adult team:
 Dr Rachel Kesse-Adu: Rachel.Kesse-Adu@gstt.nhs.uk
 Dr Kate Gardner: Kate.Gardner1@gstt.nhs.uk
 Dr Dale Seviar: dale.seviar@gstt.nhs.uk

Paediatric (Evelina):
 Dr Sabah Babiker Samah.Babiker@gstt.nhs.uk
 Dr Nick Fordham: nick.fordham@gstt.nhs.uk

Croydon Health Services NHS Trust (Mayday University Hospital)

Adult lead: Dr Stella Kotsiopoulou: stellakotsiopoulou@nhs.net
Paediatric lead: Dr Nazma Chowdhury; nazmachowdhury@nhs.net

Lewisham and Greenwich NHS Trust (Lewisham University Hospital and Queen Elizabeth Hospital)

Adult lead: Dr Tullie Yeghen: tullie.yeghen@nhs.net
Dr Kate Fletcher: kate.fletcher4@nhs.net
Paediatric leads: Dr Adebola Sobande: a.sobande@nhs.net
Dr Sarah Wilkinson: s.wilkinson6@nhs.net

4 Operational Meetings

As mandated in HCC Service Specification & to facilitate the smooth running of the HCC:

- HCC MDM Meetings: held monthly and attended by all LHT/SHT multidisciplinary teams. All clinical teams are invited to bring complex cases for discussion and formulation of MDT-based management plans. In addition, eligibility for therapies including bone marrow transplantation, Crizanlizumab, and Voxelotor are discussed for approval.
- HCC Strategy meetings: Monthly and attended by KHP Consultants and the HCC management team
- HCC Delivery meetings: Quarterly and attended by multidisciplinary teams from all four SELSE SHTs and the HCC management team.
- HCC Business meetings: Bi-annually. Each site within the HCC has the opportunity to summarise current achievements and challenges in their service and receive feedback/advice where appropriate.
- HCC Chair, Deputy Chair and HCC Network Manager weekly check-in to keep track of ongoing projects and objectives.

5 Education, Training, Staff and Patient Engagement

To maintain the highest clinical standards and to improve patient experience through delivering equitable standards of care across the region, our HCC continues to build upon the established network educational programme. This work continued throughout 2024-25, as we adopted new ways of working to deliver education and training.

5.1 Peer Education Meetings

SpR education sessions:

Virtual teaching / revision sessions, delivered during an evening slot throughout the week, were successfully piloted in Sept '23. This format continued in 2024-25 with the team delivering sessions twice during the year:

- w/c 2nd Sept 24
- w/c 28th Feb 25

Network Education Event:

The network education event took place on 6th Nov 24 and included discussion on the 23-24 Network pain audit results and plans for improvement in 24-25. The event also included a focus on Parvovirus in SCD, including case studies and expert panel discussion between Clinicians across the network (Agenda in [Appendix 13.1](#)).

5.2 Nurse led Education

The SELSE HCC network offers a variety of training and education modules across the year. Nurse Educator, Chifundo Stubbs, helped develop a full programme of face to face and virtual teaching across the network.

This year's teaching was aimed at Nursing and Allied Health Professionals (AHP), patients and the general public. Nursing and AHP education was focused on addressing issues raised by the No One's Listening event and the HCC's own patient feedback. Patient education was focused on empowering patients with the latest knowledge and therapy development to help enable true partnership between patients and clinicians. Education of the general public was aimed at raising basic awareness of Sickle Cell in an attempt to reduce the stigma that Sickle Cell patients experience.

In addition to the above the SELSE HCC also collaborated with Trust **Staff Network and the Equality Diversity and Inclusion (EDI) teams** to raise awareness among staff by holding stalls at Staff Networks and EDI events.

April 2024 – March 2025 Kings Nurse Teaching Sessions and Transition Activity Report:

- Adult CNS Bitesize ward teaching sessions on average every fortnight. No written feedback, however, well received with excellent participation by attendees which has included Nurses, Healthcare Assistants, and AHPs as well as Nursing students. Average 6 participants per session.
- Adult CNS delivered 3 management of Sickle Cell crisis in pregnancy sessions to the Kings Denmark Hill Midwifery team. Overall rating between 4/5 for each session
- Roald Dahl Transition Nurse delivered ACT NOW national webinar to healthcare professionals focusing on emergency Sickle Cell disease management and pain relief. Over 180 attendees. This was an NHSE initiative, March 2025
- CNS continue to facilitate monthly (each 2nd Thursday) patient support group information sharing, including updates on new therapies, and self-management of condition awareness sessions e.g. accessing welfare, social work and psychology support. Average attendance 12 patients.
- CNS delivered one session of Red Cell disorders teaching as part of the Kings Academy Haematology Malignancy Course (23/01/24). The session was well received and scored 5/5. This is an ongoing annual commitment by the Lead Adult Sickle CNS.
- CNS remains member of Pfizer's Peer 2 Peer Sickle Cell education committee, attending committee meetings, contributing to the development of education slide- decks material for healthcare professionals.
- CNS presented and participated in Q&A at the official launch of Voxelotor (Jul 2024) and the role of the CNS within the MDT.
- Transition Lead CNS organised two transition workshops for teenagers preparing or who have recently moved to the Red Cell adult service: Jan 2024; 12 attendees, and Jul 2024; 15 attendees, excluding parents. These were very informative days and an opportunity for the young people to meet other young people living with Sickle Cell and Thalassaemia. They expressed finding the tour of the adult ED and meeting staff in the department particularly reassuring.
- Transition Lead attends the weekly Paediatric clinic to meet patients age 14 to 17, and in line with the KCH transition pathway commence the transition process by introducing self, getting to know the patients, their carers and facilitating discussions around self-management and medication compliance. In addition, patients who consent are referred to the Sickle Society Peer to Peer mentoring service. On average the transition CNS can attend consultations with about 5 patients on any given clinic day. However, due to scheduling of clinic slots e.g. patients given same time slot and allocated to different doctors, it's not possible to see all transition age patients who are on the list on some days. Thus, she compensates for this by attending the post clinic debrief meetings.
- The transition CNS has attended monthly Psychosocial meetings and participated in the development of additional support for identified vulnerable patients, including liaising with Social Services where necessary.
- The Transition CNS continues to facilitate the monthly ADT clinics, ensuring that patients are called to remind of appointments at least a week in advance and pre-ordering blood tests and guiding patients on where to go

for the blood tests e.g. 17 years olds to attend adult phlebotomy service. The CNS also ensures that patients transitioned during the ADT clinics are supported with accessing red cell exchange service or top up transfusions where clinically indicated. She ensures that she maintains contact with those on Hydroxycarbamide to encourage adherence. Other support provided to transition patients include welfare officer referrals for PIP applications and appeals, housing letter, extenuating circumstance and extra exam time letters.

- Sickle Cell awareness day 19th Jun 2024 organised and facilitated by the KCH Sickle team. Good public response with visitors to the Golden Jubilee Wing and staff stopping at the stall to learn more about Sickle Cell disease.

Report written by: Virginia Tshibangu, Roald Dahl Transition Clinical Nurse Specialist

Our KCH Paediatric team have provided the following teaching/education sessions in the same 12month period

- 1st April 2025 – Elmgreen Secondary School SCD Teaching (Teams)
- 1st April 2025 – T&G SCD Induction for Newly Qualified Nurses (In person)
- 4th March 2025 – NQN on rotation SCD induction (In person)
- 30th January – New Starters SCD introduction (In person)
- 10th December 2024 – Introduction to SCD: T&G Induction (In person)
- 7th November 2024 – St Michael’s College SCD Meeting
- 6th November 2024 – Richard Challoner School teaching (Teams)
- 2nd October 2024 – Rockmount Primary School SCD Teaching (Teams)
- 12th September 2024 – Marian Vian School SCD Teaching (Teams)
- 27th August 2024 – Paeds ED Team Day SCD Teaching (In person)
- 20th June 2024 – St John’s Catholic Comprehensive School SCD Teaching (Teams)

Patient and Public Education

We continue to seek opportunities for our patients to be expert panellist at health inequality events in our region. HCC Patients have attended Applied Research Collaboration (ARC) South London Knowledge Exchange in Mar 2024 and are due to present at this year’s KHP conference and will be attending ASCAT later on this year.

Patients are actively involved in SELSE HCC Sickle Cell Awareness events and our SELSE HCC education days, during which they share their lived experience stories with attendees.

Community Event

SELSE HCC have held stalls to raise awareness at several Black Health and Wellbeing events in an effort to raise awareness and work towards reducing the stigma in the community.

- | | |
|---|------------------|
| • ASCAT Conference 2023 | 25 – 28 Oct 2023 |
| • Croydon BME Forum | 12 Mar 2024 |
| • ARC South London Knowledge Exchange | 19 Mar 2024 |
| • Clinical Research Network Sickle Cell Event | 18 May 2024 |
| • Inspire London – Peckham | 25 May 2024 |
| • Lambeth Black Health event | 6 Jul 2024 |
| • Croydon Sickle Cell Support Group Annual Walk | 20 Jul 2024 |

Outcome and Highlight

- Future collaborations with organisers of the above events
- Request for more information on Sickle Cell from the general public.
- Patients sign-posted to the Croydon Sickle cell and Thalassaemia Centre and Woodenspoon house.
- Patient invited to future events to share their stories
- Request for information on how to donate blood.
- Member of the public shared about the formation of OSCAR and how they used to raise funds for Sickle Cell in the 1970's and 1980.
- Connected with a charity who work with MS and Sickle Cell patients.
- Request for information to share with patients.
- Request information on testing.
- Request for an opportunity to shadow the NS team.

5.3 Vascular Scientist Education

Our Transcranial Doppler (TCD) Lead will have oversight of TCD scanning services across the HCC, including training and quality assurance programmes. Outcomes, performance data and patient feedback will be presented annually at the network management meetings. We plan to deliver twice yearly training for TCD practitioners. Our TCD lead will also work with the KHP Learning Hub to develop a suite of training materials which will be accessible to TCD practitioners across the HCC. The TCD scientists from KCH provide an outreach service to QEH, UHL, CUH and DVH and are present in the annual review clinics at these sites.

Introduction of Quality Assurance (QA):

As part of the national TCD QA team, we have agreed the template for TCD recording and the data elements for uploading into the NHR (National Haemoglobinopathy Registry). Individual practitioners will participate in the QA programme to maintain their eligibility for accreditation.

5.4 ASCAT

The renowned, annual conference of the Academy for Sickle Cell and Thalassaemia (ASCAT), curated in collaboration with European Haematology Association (EHA) and the British Society of Haematology (BSH), took place in London, on 2nd – 5th Oct 2024. There were 806 registered delegates from 58 countries including Clinicians, Nurses, Service Managers, patients, researchers and students. The theme for this year was 'Haemoglobinopathies in Focus: Global Advances, Local Disparities'.

The conference admirably responded to the 25.09.25 withdrawal of Voxelotor by including a session to focus on this matter. Session panel members included international members of relevant clinical trials teams and Data Safety Monitoring Boards. The lack of information and guidance, following the announcement, left clinicians and patients in a difficult situation which allowed the proliferation of inconsistency in advice circulating on how to manage withdrawals or implement any possible alternatives. There was discussion on the various implications that this could hold for future clinical trials. Suggestions for the future included an insistence of pharmaceutical companies to more deeply involve investigators at every level/stage of the trial process. Also identified was a need for countries with less experience in clinical trials to be supported in bolstering their ethics and granularity of data and analysis.

The 2024 meeting is scheduled for 2-5 Oct 2024 at County Hall, London.

5.5 SpR Training Day

In Sept 2024, SELSE HCC ran the network's training day for SpR delegates to support their knowledge of Haemoglobinopathies and to help in their preparation for MRCPATH examinations. To improve access for trainees, the format was changed to be a series of evening lectures delivered online over the course of a week. Registration for the course remained free. Attendance at each session was around 30-40 (we had planned to limit at 25, but due to demand,

additional places were offered). Although formal feedback was not obtained, about 10 emails from trainees were received who had attended to extend gratitude and compliments

We continued to provide this on a virtual platform to allow equitable access for trainees across the country. Delegates come from across the UK and Ireland. Requests to attend this course continue to outstrip capacity demonstrating this is a well-received and well-regarded training course among Haematology trainees nationally. We will seek formal feedback for these sessions going forward to help us continue to improve the course we offer.

5.6 Guidelines

SELSE HCC holds monthly guidelines meetings for both Adult and Paediatric services. The group continues to update guideline information relating to specific clinical protocols and patient pathways. These guidelines provide information to members of the network which can be amended and ratified at local level by network SHT and LHT sites. The guidelines are circulated to the network and updated on the STSTN website.

5.7 Website

SELSE HCC continues to maintain an active website which has now moved away from the original STSTN banner. The website is being revamped and updated. We have obtained a domain referring to the SELSE HCC (www.selsehcc.org.uk) however still able to access the website with URL (www.ststn.co.uk). This platform provides useful information to patients, clinicians and those with an interest in Haemoglobinopathies. Items published include patient forum information, clinic and contact information, education, guidelines, research, Red Cell Newsletters and latest news items. The network also has a twitter account and a YouTube channel.

5.8 HCC/STSTN Newsletters

The HCC/STSTN Red Cell Newsletter has continued publication at twice a year. Red Cell News is published across the network hospitals including delivery of hard copies, and electronic copies are on our website (www.selsehcc.org.uk) and available via social media. The newsletter contains information relevant to Sickle Cell and Thalassaemia patients, articles written by patients and news from the HCC/STSTN network. This year we have also included pieces by Psychology teams and nutrition/dietetics teams.

5.9 Patient Forums

The network's patient forums remain online since the pandemic. They are active throughout the year with the virtual platforms established providing an important continued monthly support network for our patients. Some sites have returned to some in person meetings and there have been moves to encourage patients to take a more active role in the planning, organisation and input of patient support groups with continued facilitation and enablement by CNS's, Psychologists and network support staff.

5.10 Patient Awareness Day

An online Sickle Cell patient awareness day was held in Jul 2024 with a paediatric morning session and adult afternoon session. This was attended by ~60-70 patients and their relatives, including >70% who had not attended this event before.

Topics covered included acute complications in childhood, transition to adult services, making use of welfare support, psychological services, blood transfusion, stem cell transplantation, available patient support groups as well as hearing patient perspectives and an active question and answer session. The day received very positive feedback. We also received constructive comments on topics and content patients would like to have included in future sessions and we will incorporate this into this year's scheduled sessions on 13th Jul 2025.

Event Feedback:

22 responses submitted

Overall, how satisfied are you with the event?

4.82



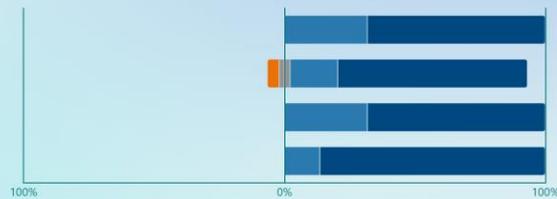
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22 responses submitted

How would you rate the following?

Not well at all Not very well Somewhat well Very well Extremely well

sessions were presented in a clear and easy-to-understand way
Maintained my interest throughout the duration of the event
Encouraged attendee participation
Thoroughly answered questions from participants



< 6 of 11 >

Summary of Comments – Potential areas for future focus: -

Future Events

- Q&A after each presentation
- Increase patient representation (note – difficulty in identifying willing patient representatives)
- Future topics – diet & nutrition, exchange blood transfusions, pain management
- Publish presentations

Key Focus Areas

- Training & Education across healthcare staff to improve understanding of SCD
- Information on new treatments

Patient Information Requests -

- Housing – how to access information / who can assist?
- Psychology – how to access information / who can assist?
- PIP – detailed information on PIP

- New Treatments

5.11 Teenage Transition Workshops

A teenage Transition workshop was held at KCH, in Jan 2024. This was the first such workshop after a long period of absence, a consequence of significant staffing issues that affected the transition nurse specialist post over the last 2 years.

The workshop was attended by 20 young adults and positive feedback received for all the sessions throughout the day. We plan to run these sessions twice a year, in conjunction with the specific transition clinic that happens monthly.

At GSTT, these events also run bi-annually and are well attended, with between 6-10 young adults plus their parents in attendance at each event.

6 Peer review, Audit and PREM (Patient Reported Experience Measures)

6.1 Peer review

Peer Review was conducted across the network in early 2024, including on-site inspections at Guy's St. Thomas's Hospitals, Evelina London Children's Hospital, King's College Hospital, University Hospital Lewisham, Queen Elizabeth's Hospital in Woolwich, and Croydon University Hospital.

Although there was a huge amount of work involved in preparation for Peer Review, the Red Cell teams on all sites supported the inspections and were rewarded with some very positive feedback. There were several significant issues highlighted across the network. Some issues such as inadequate staffing were global problems, whereas there were other more local issues including the inadequate estates at King's College Hospital Adult services Haematology outpatient and outpatient Pharmacy.

Areas highlighted as being inadequate have enabled local teams at each Trust to lobby for improved services, staffing, and estates for this often-underserved patient group.

We are particularly grateful for the service users including patients with lived experience of Sickle Cell disease and the services under inspection, as well as parents and carers of patients, who attended either in-person or online for the inspections and gave their feedback to the peer reviewers.

We are also grateful to the team of peer reviewers who put considerable time and expertise into reviewing each SHT service across the network, as well as the HCC, many travelling significant distances across England to undertake the Peer Review process.

6.2 PREM survey

Patients with Sickle Cell disease (SCD) frequently experience poor quality of care, often due to a lack of awareness of the condition among non-specialist staff, pre-conceived biases, and unfounded allegations of drug-seeking behaviour. Multiple reports and surveys using Patient-Reported Experience Measures (PREMs) tools highlight widespread issues such as delayed and ineffective pain relief provision in emergency departments, limited access to psychological therapies, and inadequate funding for service development.

Following the distribution of the 2023 PREMs analysis results by Dr. Chakravorty, the Specialty Health Teams (SHTs) were asked to provide updates on improvements identified through the Patient Improvement Questionnaire. The primary aim of this analysis was to revisit critical patient concerns and to highlight areas where meaningful progress has been made. In response to the 2023 PREMs data, teams were requested to

outline three key quality improvement initiatives implemented to address patient feedback. These initiatives demonstrate ongoing efforts to enhance patient experience and promote patient-centred care throughout the service. Key actions taken by GSTT and KCH are summarised below, with further detail provided in the Appendix. Actions taken by Croydon University Hospital and Lewisham and Greenwich Trust are not reported.

6.2.1 GSTT

In addition to the analysis of 95 responses in the 2023 HCC-wide PREM survey for GSTT adults, GSTT also held a patient event in May 2024 to discuss the findings and ensure patient input into plans proposed to respond to issues raised from PREMS and PEER review. The four key themes were Specialist, Emergency, Ward, and Information / support with problematic areas in 9 categories where >50% patients had a 'problem' with the issue. Detailed results and actions are provided in [Appendix 13.2](#)

Emergency Dept knowledge of SCD & prompt administration of pain relief:

- Implementation of e-learning in 2024 (compulsory for senior ED staff); > 1100 staff completed with follow up staff survey confirmation that training impacted on staff attitude.
- Ongoing nursing teaching via sickle nurses and ED sickle-link nurses (4 link nurses in ED in 2024) – including medical and psychological aspects.
- Ongoing medical teaching & MDT
- Universal Care Plan (UCP) implementation completed Jul 24

Wards: Suitability for age & sufficient staffing:

- Two new wards since PREMS and an area suitable for younger patients but we do still have a high number of outliers
- Regular teaching to nurses on all wards with SCD patient admissions
- Staffing issues ongoing due to wider NHS problems; do still intermittently have wards that have bank nurses but this is much improved from 2023

Handover of information between HCP:

- Ensuring only salient points of the history are confirmed when transferred from STH ED to Guys
- SCD Trust website for leaflets

Patient information on treatment options and peer support for SCD:

- Created QR codes for patient information leaflets and also have hard copies to post out. Can also append to clinic letters
- Discuss research opportunities in OPA
- Regular weekly support group and now have a young person's group; this is advertised proactively to patients and careers by direct email, posters in Reception areas, leaflet provided by CNS in person and by post attached to clinic letter.
- Peer mentoring program for under 25s via sickle cell society

Access to Psychologist or Counsellor:

- Increased Psychology service presence during Tues clinics and at patients' annual TCD scan to offer more thorough screening for potential cognitive and/or learning difficulties as well as emotional wellbeing. Prioritisation of new patients.

6.2.2 KCH

The 57 responses in the 2023 HCC-wide PREM survey for KCH adults were analysed. The four key themes were Specialist, Emergency, Ward, and Information / support with problematic areas in 9 categories where >50% patients had a 'problem' with the issue. KCH selected five problem areas and used these as the basis for quality improvement measures to embed in routine services. Detailed results and actions are provided in [Appendix 13.3](#)

Emergency Dept knowledge of SCD & prompt administration of pain relief:

- 12 Bitesize teaching sessions delivered in the Emergency Department per year
- 6 monthly 1.5-hour sessions for ED Residents per year
- Campaign for e-learning module to be mandated for all ED staff with enamelled metal sickle badges for those who have completed training
- UCP implementation Mar 2024, now >90% complete
- Implement and maintain updated Epic sickle alert and Epic Care Plan pops ups
- ACT NOW launch as a pilot site 21st May 2024, now embedded in routine teaching

Patient information on treatment options and peer support for SCD:

- Production of a leaflet outlining treatment options
- HCC illustrated Hydroxycarbamide leaflet inserted into clinic letters by Epic short code
- Gene Therapy information leaflet produced in Feb 2025, after Jan 2025 NHS approval of funding for Gene Therapy in selected cases, appended to letters of interested & eligible patients
- Re-launched patient support group which is now run by patients and supported by CNSs, meeting regularly face to face or virtually
- Regular face to face transition workshops for 16-19 year olds

Access to Psychologist or Counsellor:

- Successfully recruiting an additional full-time Psychologist
- Referral of patients to Enhanced Community team monthly online psychology workshops

6.3 Audits

6.3.1 Sickle Cell Disease Acute Pain Episode Audit 2024- Implementing NICE guidance

The aim of this audit is the assessment of the management of Sickle Cell disease acute pain presentations within the SELSE HCC Network compared with published NICE standards in hospital sites.

The 2025 annual pain management audit analysed data collected electronically via a standardised Microsoft forms questionnaire, that was sent to all the SHT and LHT sites within our HCC. Data collection spanned 4 weeks in March 2025. A total of 186 entries were made, 138 adults and 48 children. The youngest patient was 1 year old, the oldest 70 years old, with a mean age of 28.08 years. 55% of patients were male, 43% female, 2 % did not disclose gender. Please see patient numbers at each centre in figure 1.

There were 105 (56%) walk-ins, and 81 (44%) London Ambulance Service (LAS) presentations. The only HASCU within our HCC is at the adult UHL site, where 17 patients were seen during the audit period.

Hospital	Children	Adults	Total
GSTT NHSFT (Guy's and St Thomas', Evelina Children's Hospital)	19	71	90
King's College Hospital NHSFT (KCH, Princess Royal University Hospital Orpington)	17	18	35
Croydon University Hospital	2	8	10
Queen Elizabeth Hospital	7	13	20
University Hospital Lewisham	3	17	20

Brighton + Sussex University Hospitals (Princess Royal Sussex, Royal Sussex, Royal Alexandra Children's)	NR	1	1
Dartford and Gravesham NHST (Darent Valley Hospital)	NR	9	9
East Kent NHSFT (Kent + Canterbury, William Harvey, QEQM Hospitals)	NR	NR	NR
East Sussex NHST (Conquest, Eastbourne)	NR	NR	NR
Maidstone + Tunbridge Wells NHSFT (Maidstone Hospital, Tunbridge Wells Hospital)	NR	NR	NR
Medway NHSFT	NR	1	1
Western Sussex Hospitals NHSFT (St Richard's, Worthing Hospital)	NR	NR	NR
Total	48	138	186

Table 1. Data collection forms returned per site

Overall, 86.56% of all patients had assessment of pain at presentation. All services had 100% compliance with pain assessment at presentation, except two sites, GSTT adult and KCH paediatric site, where 21 and 4 patients respectively were not assessed for pain at presentation.

The percentage of patients offered analgesia within 30 minutes of presentation was 63.98% (119/186) throughout the whole HCC. Below are services grouped by proportion of patients offered analgesia within the 30-minute target.

- 70 – 100% of patients: KCH paediatric, QEH paediatric, UHL adult, CUH paediatric, Medway hospital.
- 40 – 70% of patients: KCH adult, GSTT adult, GSTT paediatric.
- 10 – 40% of patients: QEH adults, CUH adults, DVH, UHL paediatric.

The mean time (in minutes) between presentation and first analgesia was **35.3 minutes** in those who walked-in to ED. Times to analgesia in LAS patients is unlikely to be accurate due to variability in recording of analgesia received in ambulance. Times to analgesia for LAS patients ranged from 10 minutes to 294 minutes. Below are the sites grouped by average time to analgesia:

- < 30 minutes: KCH paediatric (25.4 minutes), CUH paediatric (24 minutes), QEH paediatric (28.8 minutes), UHL adult (16.6 minutes)
- 30 – 45 minutes: KCH adult (34.4 minutes), GSTT (35.56), GSTT paediatric (36.25), CUH adult (45 minutes)
- 45 minutes: QEH adult (54 minutes), UHL paediatric (142 minutes).

Out of those receiving analgesia, only 36.56% had re-assessment of pain every 30 minutes until pain relieved or discharged. In contrast 80.65% had pain assessed every 4 hours thereafter. This may reflect practice on the wards, however only 34% of patients were admitted to inpatient wards. A miniscule 1% had clinical assessment every hour while on strong opioid, although again, reporting here may be inaccurate.

For the KCH adult service, additional information showed that a total of 53 patients presented with pain during the audit period, 24 of which were LAS presentations. 29 patients walked-in to ED, average time to analgesia was 34.3 minutes. 55% of patients received analgesia under 30 minutes and 79% received analgesia under 45 minutes.

Patients presenting with moderate pain (score 4-7), 65% were offered a strong opioid, 18% were not offered a strong opioid, 5 % were offered a weak opioid instead, 12 % had already received an opioid prior to presentation. No patients were offered pethidine.

Summary:

1. Overall improvement in time to analgesia across the HCC, compared to previous years, however, more effort needed to ensure adherence to the 30 minute analgesia target . There are a few outlier patient episodes that have skewed times to analgesia in some centres. Also lack of robust LAS time to analgesia affects overall times.
2. Outstanding excellent results from UHL adult service reflects positive impact of HASCU, demonstrating need to adopt good practice in other centres.
3. Paediatric patients generally received analgesia faster than adults. Great variability in adult services, at times impacted by patient refusal.
4. Pain re-assessment every 30 minutes following analgesia remains very poor across the whole HCC. Similarly, hourly assessment of patients on strong opiates was suboptimal. Emphasis on re-assessment to be made when delivering teaching to ED colleagues, and ward staff.
5. Continuous collaboration with ED colleagues, utilising UCP, EPIC, NHS app, E-learning, NHS cards, ACT NOW acronym.
6. Focus on outlier services, identify gaps, aim to rectify shortages.

7 HCC SELSE Statistics

7.1 HCC SELSE – Number of Patients across HCC SELSE Network

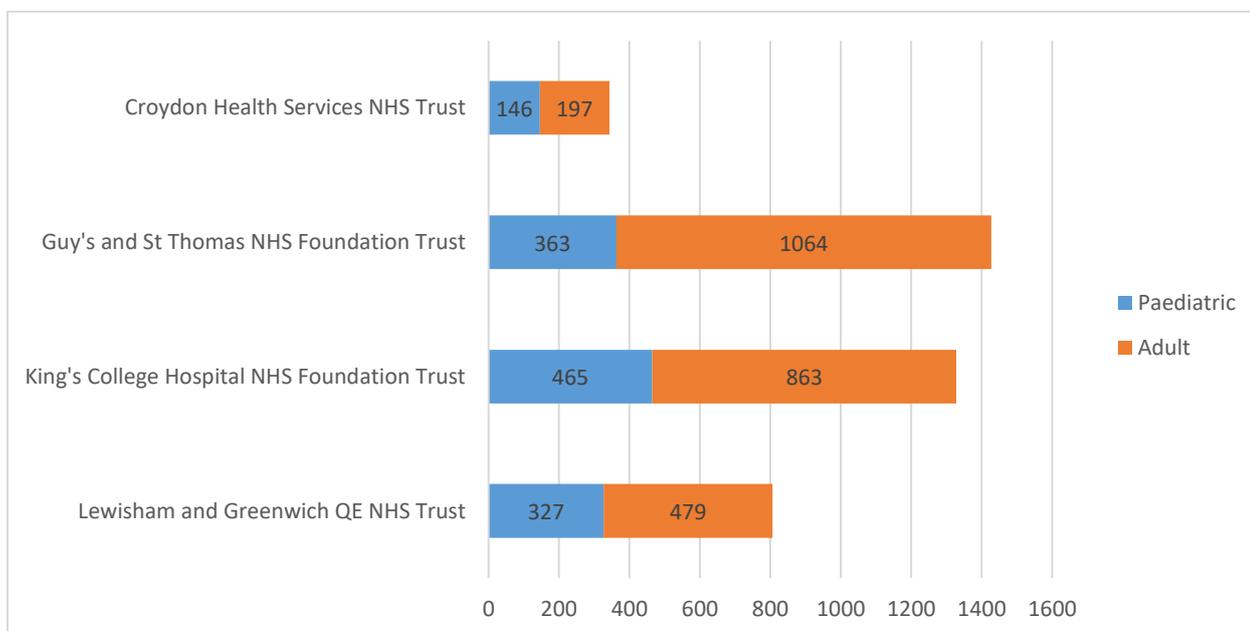


Figure 1. SELSE HCC Number of Patients Registered with Network Trusts FY 24-25

7.2 HCC SELSE - Patient Admissions

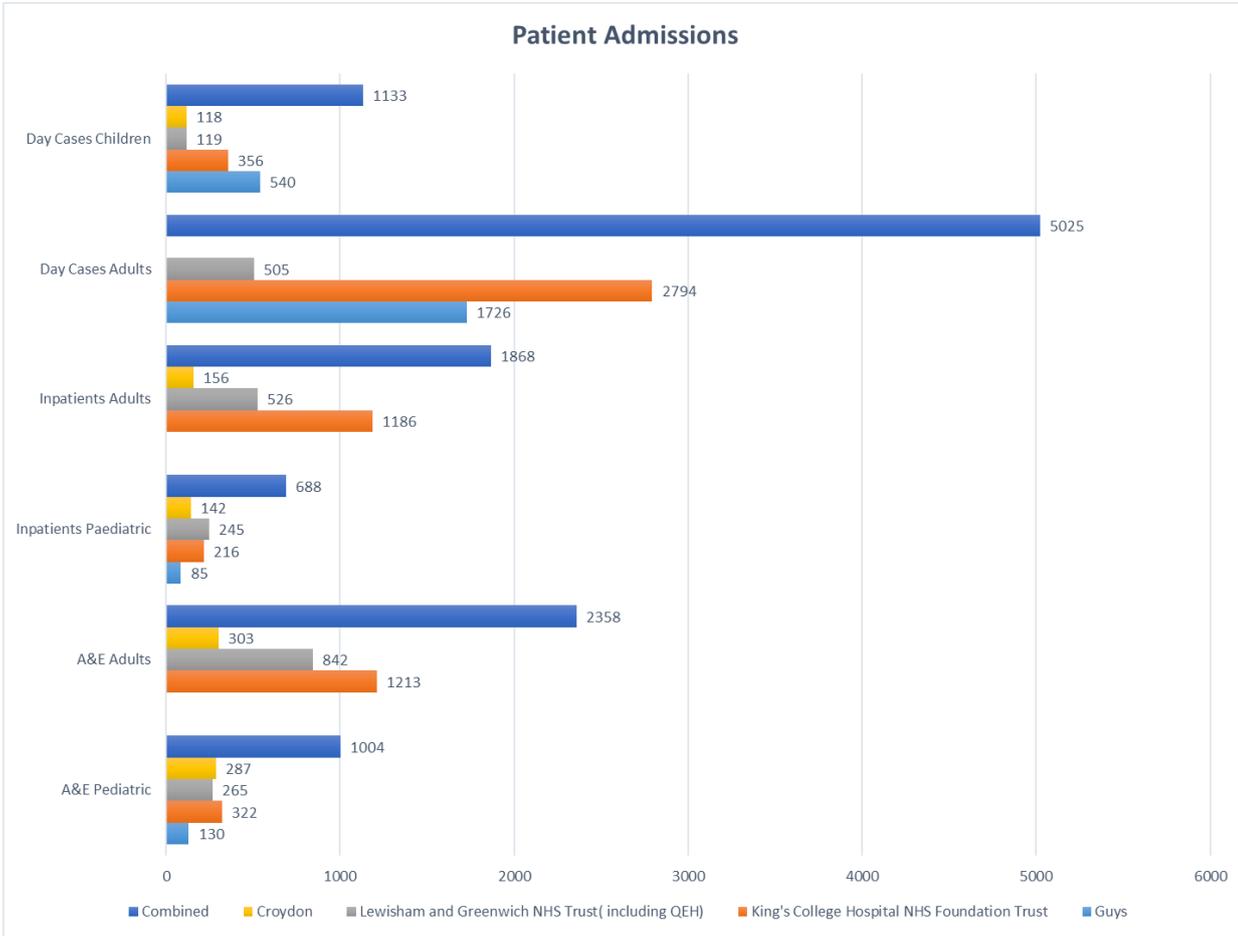


Figure 2 – SELSE HCC Admissions (GSTT Adult A&E and Croydon Adult Day Case data unavailable)

7.3 HCC SELSE - Number of Pregnancies and Births

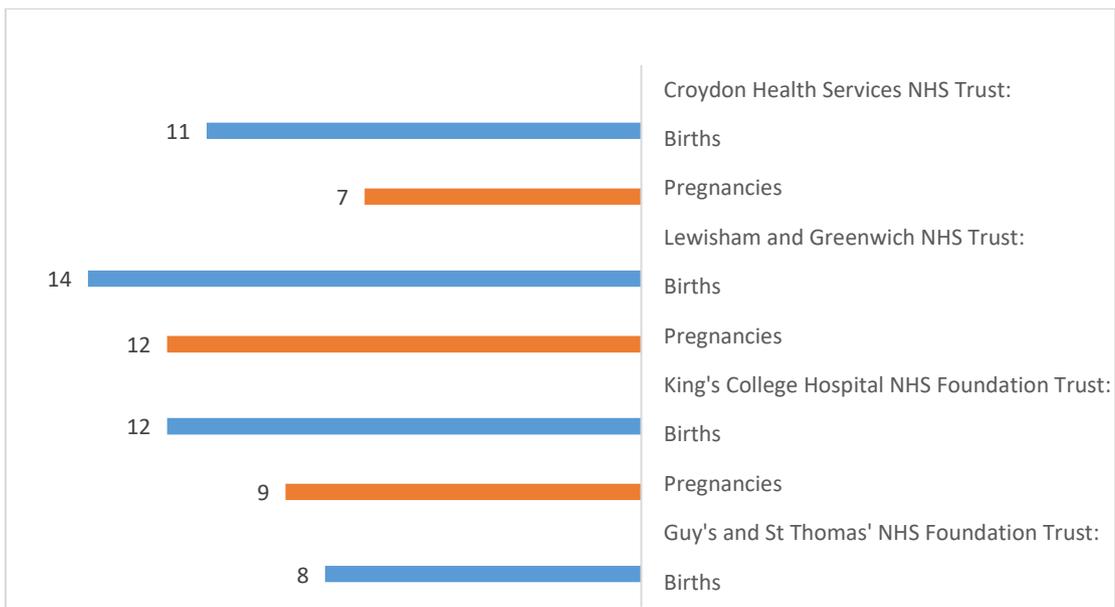


Figure 3. SELSE HCC Number of Pregnancies and Births

7.4 HCC SELSE - Number of Deaths

Croydon Health Services NHS Trust	4
Guy's and St Thomas' NHS Foundation Trust	5
King's College Hospital NHS Foundation Trust	8
Lewisham and Greenwich NHS Trust	1
Total	18

Table 7-1 HCC SELSE Number of Deaths

7.5 HCC SELSE - Number of Transitions from Paediatric to Adult Services

Croydon Health Services NHS Trust	5
Guy's and St Thomas' NHS Foundation Trust	25
King's College Hospital NHS Foundation Trust	29
Lewisham and Greenwich NHS Trust	13
Total	72

Table 7-2 HCC SELSE Number of Transitions from Paediatric to Adult Services

7.6 HCC SELSE - Number of Patients on Hydroxycarbamide

	Paediatric	Adults	Total
Croydon Health Services NHS Trust	80	115	195
Guy's and St Thomas' NHS Foundation Trust	172	250	422
King's College Hospital NHS Foundation Trust	224	323	547
Lewisham and Greenwich NHS Trust	103	119	222
Total	579	807	1386

Table 7-3 HCC SELSE - Number of Patients on Hydroxycarbamide

7.7 HCC SELSE - Number of Bone Marrow Transplants

	Paediatric	Adults	Total
Croydon Health Services NHS Trust	0	0	0
Guy's and St Thomas' NHS Foundation Trust	0	4	4
King's College Hospital NHS Foundation Trust	0	6	6
Lewisham and Greenwich NHS Trust	0	0	0
Total	0	10	10

Table 7-4 HCC SELSE - Number of Bone Marrow Transplants

7.8 HCC SELSE – Number of Patients Started on New Therapies (Crizanlizumab/ Voxelotor) Patients are no longer on these medications.

During the financial year 2023/2024 patient access to all new therapies, including Crizanlizumab and Voxelotor were withdrawn. We therefore have no patients using these two novel therapies, and continuing to look to the future for new agents, including gene therapy to become available.

7.9 SELSE HCC - MDM

SELS E HCC continued to hold a virtual monthly Multi-Disciplinary Meetings, chaired by Dr Arne de Kreuk and Dr Nick Fordham as the Deputy Chair. The group continued to meet regularly to review complex cases across the region requiring collective senior clinical input. 52 cases were discussed in the period under review and the types of cases and sources of these referrals is outlined in the table below.

The HCC MDM refers cases as required to the NHP MDM, in line with NHSE policy. We referred 11 cases to the NHP during this period of review. Nine of these were gaining approval for sibling bone marrow transplant according to the eligibility criteria. The other two cases were to review complications of blood transfusion.

Description	Number of Cases
Mortality	20
Morbidity	4
Transplant	5
General/treatment	8
Gene Therapy	2
Voxelotor	13
Total Cases	52

Hospital	Number of Cases
CUH	5
ELCH	1
GSTT	21
KCH	19
LGT	3
PRUH	1
MEDWAY	2
Total Cases	52

Table 7-5 SELSE HCC MDM Number of Cases by Description and Hospital

7.10 SELSE HCC – M & M

This M&M review covered 12 cases of patients with Sickle Cell Disease (SCD) or related Haemoglobinopathies across the SELSE network. Patient ages ranged from **19 to 64 years** (mean \approx **42 years**).

Causes of death included acute complications (pulmonary thromboembolism, acute chest syndrome, delayed haemolytic transfusion reaction with fat embolism syndrome, intracerebral haemorrhage, parvovirus infection with multi-organ failure), as well as chronic progressive disease (hepatorenal syndrome, decompensated sickle hepatopathy, right heart failure in pulmonary hypertension). In some cases, the cause of death remained unclear due to absent post-mortem examination or lack of external information.

Distribution of Causes of Death by Category (SELSE M&M 2024/25)

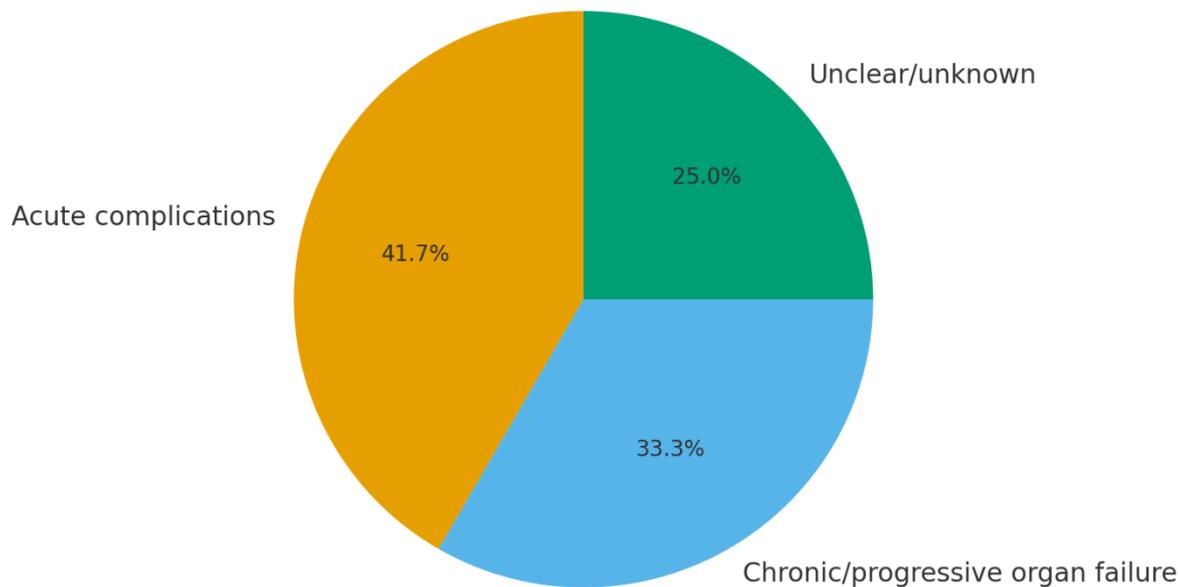


Figure 4 Distribution of Cases of Death by Category - SELSE M&M 24/25

Learning points and shortcomings in care:

- Recognition and escalation:** A case of acute chest syndrome highlighted inadequate clinical responses, with dangerously low Hb and SpO₂ values being recorded as “adequate.” Similar concerns arose in another case where the patient was lost to follow-up, contributing to delayed recognition of right heart failure.
- Systemic delays:** A 19-year-old patient died following a 111 call that was never returned; Hydroxycarbamide supply interruptions were also noted.
- Governance gaps:** In one trust, medical leadership failed to acknowledge serious shortcomings despite clear evidence of avoidable deterioration. This prompted recommendations from the HCC MDT for mandatory induction on acute SCD management for Haematology registrars.
- Emerging complications:** Parvovirus infection was repeatedly linked to rapid deterioration with fat embolism and hyper-inflammatory syndromes, suggesting the need for routine reticulocyte checks, early admission, close monitoring, and timely transfusion or plasma exchange.
- Complex comorbidities:** Older patients presented with multiple organ involvement (renal, hepatic, pulmonary, and cardiovascular disease). These cases highlighted challenges in securing multidisciplinary care, with other specialties reluctant to assume responsibility, leaving Haematology teams overstretched.
- Unclear deaths:** In several cases occurring outside London or without post-mortems, cause of death could not be established. This revealed gaps in communication pathways and difficulties in obtaining external information.

Themes emerging from this review include:

1. Need for stronger governance and escalation pathways.

2. Improved acute care training for front-line teams.
3. Early recognition of parvovirus-related complications.
4. Better coordination with other specialties for complex comorbidities.
5. Mechanisms for capturing information on deaths occurring outside specialist centres.

7.11 HCC SSQD 2024-2025

Indicator	Theme	HCC Indicator 2024-25	Data	Status	Notes
HAEMCC09bi	Referrals	Proportion of patient deaths discussed at Haemoglobinopathy Coordinating Centres (HCC) morbidity/mortality meetings	100%	✓	
HAEMCC09c	Referrals	Proportion of serious adverse events that are discussed at the HCC morbidity/mortality meetings	100%	✓	
HAEMCC10a	NHR database	Proportion of patients with haemoglobinopathies within the HCC network recorded on the National Haemoglobinopathy Registry (NHR)	3919	>	Number of patients registered on NHR
HAEMCC13	SHT Clinical reps	Proportion of Specialised Haematology Teams (SHT) within the HCC network with a clinical representative at all HCC multi-disciplinary Team (MDT) meetings	100%	✓	
HAEMCC14	LHT Clinical reps	Proportion of Local Haemoglobinopathy Teams (LHTs) within the HCC network with a clinical representative at all HCC MDT meetings	12.50%	✓	
HAEMCC15	Serious Adverse events	Proportion of patients with thalassaemia or rare inherited anaemia (RIAs) within the HCC network who have had a serious adverse event	ND	✓	
HAEMCC16	Serious Adverse events	Proportion of patients with sickle cell within the Haemoglobinopathy Coordinating Centre (HCC) network who have had a serious adverse event	ND	✓	

Table 7-6 HCC SSQD 2024-2025

7.12 SHT SSQD 2024-2025

Indicator	Theme	SHT Indicator 2024-25: KCH,GSTT,L&G,CRO	Data	Status	Notes
HAEM02i	TCD monitoring	Proportion of paediatric patients (aged between 2 and 16 years old) within at risk group (S/S and S/bets 0 Thal) receiving transcranial Doppler monitoring	87%	✓	
HAEM04Ai	Screening to access to specialist care	Proportion of paediatric patients with possible sickle disorders identified by neonatal screening who have been entered onto care pathway	91%	✓	
HAEM04Bii	Screening to access to specialist care	Proportion of eligible paediatric patients beginning antibiotics at or before 3 months of age as per screening programme guidelines	77%	✓	
HAEM05i	Annual review via NHR	Proportion of annual reviews recorded by NHR	70%	✓	
HAEM06Aii	Adequacy of chelation	Proportion of eligible patients on long term transfusion who receive cardiac MRI	65%	✓	
HAEM07a	Utilisation of Hydroxycarbamide paediatrics	Proportion of eligible children (> 9 months of age) who are offered Hydroxycarbamide	79%	✓	
HAEM08a	Utilisation of Hydroxycarbamide adults	Proportion of eligible adults who are offered Hydroxycarbamide	57%	✓	
HAEM09c	Assessment of modality of regular transfusion programmes sickle cell paediatrics	Proportion of regularly transfused paediatric sickle cell patients on an automated transfusion programme (simple top-up transfusions)	74%	✓	
HAEM09d	Assessment of modality of regular transfusion programmes thalassaemia paediatrics	Proportion of regularly transfused paediatric thalassaemia patients on an automated transfusion programme (simple top-up transfusions)	7%	✓	
HAEM09e	Assessment of modality of regular transfusion programmes sickle cell adults	Proportion of regularly transfused adult sickle cell patients on an automated transfusion programme (simple top-up transfusions)	6%	✓	

HAEM09f	Assessment of modality of regular transfusion programmes thalassaemia adults	Proportion of regularly transfused adult thalassaemia patients on an automated transfusion programme (simple top-up transfusions)	95%	✓
HAEM10c	Assessment of modality of regular transfusion programmes sickle cell paediatrics	Proportion of regularly transfused paediatric patients on an automated transfusion programme (manual exchange transfusion)	2%	✓
HAEM10d	Assessment of modality of regular transfusion programmes sickle cell adults	Proportion of regularly transfused adult patients on an automated transfusion programme (manual exchange transfusion)	0%	✓
HAEM11c	Assessment of modality of regular transfusion programmes sickle cell paediatrics	Proportion of regularly transfused paediatric patients on an automated transfusion programme (automated exchange transfusion)	20%	✓
HAEM11d	Assessment of modality of regular transfusion programmes sickle cell adults	Proportion of regularly transfused adult patients on an automated transfusion programme (automated exchange transfusion)	93%	✓
HAEM12	Patients referred for HSCT	Proportion of patients having an annual reviews recorded by NHR that are referred for HSCT	1%	✓
HAEM14	Sickle cell patients with serious adverse events	Proportion of Sickle cell patients having a serious adverse events	1%	✓
HAEM15	Thalassaemia/RIA patients with serious adverse events	Proportion of Thalassaemia/RIA patients having a serious adverse events	1%	✓

Table 7-7 SHT SSQD 2024-2025

7.13 HCC Self Declaration 2024-5

HCC – Progress versus Self Declaration Requirements	Status	HCC SELSE
Patient Experience	2024-25	Notes
The HCC arranges a consistent approach to the formulation of the patient experience exercise which is undertaken at least biennially	P	
The HCC will monitor a consistent approach to the patient information available in the SHTs	P	
Structure and Process	P	
There is a policy and process in place for establishing an MDT to discuss complex cases	P	Monthly HCC MDM and strategy meetings well attended and active
The HCC meets with their SHTs and LHTs at least twice a year to discuss issues relating to strategy and planning	P	
The HCC has a training and education strategy	P	

There is a named lead for trans-cranial doppler screenings	P	
The HCC attends national haemoglobinopathy panel meetings	P	
There are agreed clinical guidelines in place as detailed within the service specification	P	
The HCC will formulate and agree clinical pathways and protocols across the geographical area as detailed within the	P	
The HCC consider patients for clinical trials and other well designed studies	P	

Table 7-8 HCC Self Declaration 2024-5

7.14 SHT Self Declaration 2024-5

SHT – Progress versus Self Declaration Requirements	Status	SELSE SHT: - KCH, GSTT, L&G, CRO
Patient Experience	2024-25	Notes
The SHT participates in PREM activity and undertakes a patient experience exercise at least annually reviewing the results which arise	P	22-23 repeat PREM survey
There is agreed patient information available	P	
Structure and Process		
There is a multidisciplinary team in place as per the service specification	P	
The MDT meet at least monthly and include core members listed in 301 above	P	Observer and/or wider attendance eg LHT to be encouraged
The SHT has a process in place for TCD scanning	P	
There must be transition pathways in place as defined within the service specification	P	
The SHT agree the HCC patient pathways as per the specification	P	
The SHT agree the HCC clinical guidelines as per the specification	P	
The SHT submits data to the National Haemoglobinopathy Register	P	

Table 7-9 SHT Self Declaration 2024-5

8 Research & Publications

8.1 Clinical Trials

NCT Number	Title	Conditions	Interventions	Characteristics	Population	Dates	Participating Hospitals
NCT04624659 (4202-HEM-301)	A Study of Etavopivat in Adults and Adolescents With Sickle Cell Disease (HIBISCUS)	SCD	Drug: Etavopivat	Study type: Interventional Phase: 2/3 Study Design: Allocation: Randomized Interventional Model: Parallel Assignment Masking: Quadruple Primary Purpose: Treatment	Enrolment: 344 Age: 12-65yrs Sex: All	Study Start: 26/03/2021 Primary Completion: Dec 2025 Study Completion: Dec 2026	KCH paed GSTT adults KCH adults
NCT04285827 (CSL889_1001, 2019-001870-27)	Safety of Single Ascending Doses of CSL889 in Adult Patients With Stable Sickle Cell Disease	SCD	Biological: CSL889	Study Type: Interventional Phase: Phase 1 Study Design: •Allocation: NonRandomized •Intervention Model: Sequential Assignment •Masking: None (Open Label) •Primary Purpose: Treatment	Enrolment: 24 Age: 18 Years to 60 Years (Adult) Sex: All	Study Start: May 20, 2021 Primary Completion: July 2023 Study Completion: July 2023	Croydon University Hospital Guys and St. Thomas' Hospital
NCT04817670 VIT-2763-SCD-202	Study to Assess Efficacy and Safety of VIT-2763 (Vamifeport) in Subjects With Sickle Cell Disease (ViSionSerenity)	SCD	Drug: Vamifeport	Study Type: Interventional Phase 2 Study Design: Allocation: Randomised Intervention model: Parallel assignment Masking: Double Primary purpose: Treatment	Enrollment: 24	Study start: 09/06/2021 Primary Completion: Nov 2023 Study completion: Dec 2023	KCH adults

8.2 Other Studies:

8.2.1 Natural History Project

The Natural History Study is a large observational project looking at the natural evolution of Sickle Cell in a UK setting, established in 2021. Currently, the lack of understanding of the natural history is little understood, especially in an ageing population. We hope this real-world database of a large sickle cohort in a high-income setting will go some way to answering these questions. We are already providing frequent outputs to global conferences.

The project is now open at five UK sites: founding sites Guy's Hospital and King's College Hospital, as well as Nottingham, Manchester and Lewisham. The collected data points are all standard-of-care metrics and include laboratory, imaging, resource utilisation, and quality of life measures. The research team is the direct clinical care team plus one clinical trial coordinator at each site. Data is being analysed annually. From September 2021, we have recruited over 900 individuals but are keen to recruit as many as possible to make the results as reflective as possible of our cohort. We have presented data at recent ASH and EHA congresses.

8.2.2 BioResource

The National Institute for Health Research (NIHR) BioResource has been establishing a panel of thousands of volunteers with and without health problems from all over the country, this includes patients with SCD which is considered a rare condition in the UK. All volunteers are asked to donate a small blood sample (or sometimes saliva sample) and give consent to be contacted and invited to participate in future medical research studies, based on analysis of their samples and information they have supplied.

By recruiting thousands of volunteers with a rare disease in their family, the NIHRBR-RD aims to help with (1) the development of more affordable DNA-based tests for the diagnosis of rare diseases where the gene is known and (2) the discovery of genes causing rare diseases; currently only half of the genes for rare diseases are known.

Anonymised information and samples from the BioResource can be made available to researchers and doctors working in biomedical and healthcare research in both the public and private sector, in the UK and overseas.

Once the gene causing a rare disease has been identified, the search for better treatments can start. While not always successful, several rare diseases now have new treatments which have already dramatically improved care, giving hope that this will extend to many more in the future.

Recruitment to the Bioresource was halted during COVID-19 but will restarted in 2024 with the additional support of a Genomics England diverse data drive. Currently, over 1200 patients have been recruited across the country, of which over 200 patients have been recruited from Kings College Hospital

8.3 Publications

1. Acute chest syndrome (ACS) in sickle cell disease (SCD): pathogenesis and pharmacotherapies in early clinical development Chakravorty S, Greenough A. Expert Opin Investig Drugs. 2025 Aug 31:1-9. doi: 10.1080/13543784.2025.2551353. Online ahead of print
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9 Psychology

9.1 Psychology Service for Adults with Sickle Cell & Thalassaemia, King's College Hospital NHS Foundation Trust Annual Report 2023-2024

(Note - full version of the report can be accessed in [Appendix 13.4](#))

9.1.1 Summary

This report summarises the activity of the Psychology Service for Adults with Sickle Cell & Thalassaemia based at King's College Hospital (KCH) between Apr 2023 and Mar 2024.

Between Jul and Nov 2023, the service was fully staffed with the Lead Psychologist (B8a) and newly created Psychologist (B7) both in post. Since Nov 2023, provision of the Psychology service was further impacted by staffing changes, as the lead Band 8a Psychologist took up a new role at another Trust. This role remains vacant, initially due to unsuccessful recruitment but since Jan 2024, due to Trust financial pressure and recruitment freeze.

Clinical space constraints have temporarily eased offering greater capacity for in person appointments.

Within this time-period, the service has:

- Received 65 new referrals for psychology input from the Haemoglobinopathies team and associated healthcare professionals
- Received 8 self-referrals, exclusively from patients who had previously engaged with the service
- Reviewed
 - 107 patients for a psychological assessment and triage
 - 52 patients for outpatient psychological intervention
 - 23 patients for inpatient psychological intervention
- Reduced
 - wait times from referral to first assessment from 12 months to 4 months
 - in part this is due to the B7 working fully clinically at the expense and compromise of service development, teaching and support group facilitation and is not sustainable in the long term
- Further consolidated the role of psychology within the paediatric to adult transition pathway, in close collaboration with Maria Goridari and Dr Stacey Barkley, Clinical Psychologists in the Paediatric Sickle Cell & Thalassaemia Psychology service
- Continued to triage, refer and liaise with the Haemato-Oncology Psychological Therapies team at KCH regarding psychology assessments for adult patients with Sickle Cell Disease referred for Haematopoietic Stem Cell Transplantation

9.1.2 Further developments

- To recruit a new lead Psychologist
- To generate clinic codes on EPIC for all psychology clinics, ensuring clinical work is income generating and fully integrated into the new electronic system
- To continue supporting the haemoglobinopathies team to make all psychology referrals via the EPIC electronic system
- To establish a weekly screening and triage clinic offering first clinical contact to all patients referred within 2 weeks
- To continue attending the British Psychological Society Sickle Cell and Thalassaemia SIG, and to contribute to the ongoing development of shared good practice
- To keep strengthening connections with similar roles across this area and across the UK to share resources and learning
- To continue regular meetings and collaboration with the psychology services at GSTT and Lewisham
- Once the psychology team are fully staffed, to consider offering placements and supervision to Trainee Clinical and/or Counselling Psychologists

9.2 The Children and Young People's Sickle Cell & Thalassaemia Clinical Psychology Service, King's College Hospital NHS Foundation Trust Annual Report 2023-2024

(Note - full version of the report can be accessed in [Appendix 13.5](#))

9.2.1 Summary

This report summarises the activity for the Children and Young People's Sickle Cell & Thalassaemia Psychology Service based at King's College Hospital between April 2023 and March 2024. Within this time frame:

- 60 referrals overall were received and accepted, either for individual psychological assessment and intervention, neuropsychological assessment, group work and consultation. There is a steady increase in number of referrals.
- Neuro psychological assessment clinic and pathway has been introduced. We had to pause piloting the NIH Toolbox for cognitive difficulties screening, due information governance issues.
- Regularly attended and contributed to BPS Specialist Interest Group and the Paediatric BPS SIG.
- Attended and contributed to the National Haemoglobinopathies Panel, alternating with Dr Heather Rawle.
- The new role of Clinical Psychology in the Transition Clinic has been more robustly implemented. Both Adult and Paediatric Psychologists have brief, separate from the medical team meetings, with all the patients. Use of outcome measures screening for anxiety, low mood, cognitive difficulties. First informal, not registered feedback coming from young people and clinicians involved in the clinic is positive.
- Leaflet for psychology service had been approved by Communications team and has been circulated during clinics. Leaflet for Pica has been approved as well. Information sheet in relation to Neuropsychological Assessments is available too.
- Teaching to Local Authorities educational services, SENCO's networks and individual schools (in Lambeth, Lewisham, Southwark) continues. Invited to and did present to the pre and post registration nurse courses, in relation to the psychological impact of sickle cell and thalassaemia on children and young people and how this may present in various settings in hospital and community.
- Teaching to the IoPPN DCLin Psychology Training Course: "Clinical Psychology in paediatrics". Invited to do a bite size teaching to ED department during Team away day.
- Planning and implementation of parent's and young people's groups; Monthly Online Peer Support group for parents. Tree of life group for children and young people did not have any uptake. Leaflets/posters for both are advertised in Reception area, Outpatient Department as well as posted to families alongside clinic letters.

- Parents in Mind Group continued with running two cycles; a psychoeducational, closed, limited sessions group for parents who have children with consequent cognitive difficulties following a stroke or other brain incident/disease which may have caused such difficulties. This group was initially created and run by the clinical psychologist, Dr Emily Bennett Consultant Clinical Psychologist in Paediatric Neuropsychology at Nottingham University Hospital NHS Trust for the parents of children with acquired brain injury due to cancer. We are adapting this group, with their permission, in collaboration with the Nottingham University Hospital NHS Trust clinical psychologist in paediatric sickle cell and thalassaemia, Dr Eleanor Williams.
- Planned and implemented Consultation provision to schools (4 referrals and increasing).
- Liaising with BPS SIG psychology network as well as medical teams to advertise Parents in Mind group as well as Consultation Provision for schools.
- The service is establishing greater links with the doctoral clinical psychology training programmes and is now allocated the third trainee clinical psychologist, with plans for this to continue on a regular rotation.
- Contribution to the Standards of care for Thalassaemia and Sickle cell (i.e. Peer Review program)
- Regular, monthly, Reflective practice established for Clinical Nurse Specialists in Sickle cell anaemia and Thalassaemia and Rare anaemias.
- Focus groups organised and completed, with parents and children who had or recently have transitioned from primary to secondary school. Aim was to understand challenge and obstacles in the transition process in relation to their condition and how the team can support further and appropriately. Data under processing and outcome pending.

9.2.2 Service Initiatives and Future Developments

- Use of Q-Interactive to administer neuropsychological assessments digitally and leading to freeing time from manually scoring.
- Continue offering placement to Doc Clin Psych trainees.
- Identify and start planning next research project following completion of Focus groups.
- To regularly attend and contribute to South Thames Sickle Cell & Thalassaemia Network meetings and events.
- Continued attendance at the British Psychological Society Sickle Cell SIG:
 - a. Contribution to the development of national standards for the psychosocial care of children and adolescents with sickle cell anaemia via attendance at the BPS Psychology Sickle Cell SIG. and Steering Peer Review group
 - b. Development and contribution to BPS SIG sub-group, with specific interest in paediatrics and paediatric neuropsychological testing and screening.
- Development of rolling Tree of Life programme for patients, for all ages: separate age groups.
- Continue to roll the Parents in Mind Group. Plan to become a rolling group and extend provision to South Thames Network as well as across the country. Finding ways to advertise to services to receive referrals
- Focus Groups for children, young people and parents to help identifying difficulties at and during important transition times/periods. Followed by planning and rolling out of groups for children/young people and parents.
- Continue to liaise with SENCO's networks and Local Authorities to expand the teaching/awareness in relation to sickle cell and cognitive and learning difficulties, in the surrounding boroughs to King's College Hospital, following the example of Lambeth Council. And expand to other boroughs.
- Reviewing of the Neuropsychological Assessment Pathway. Do we need and have the capacity for baseline neuropsychological assessment?
- Potential offer of supervision to Community Psychologist in Sickle cell & Thalassaemia.

9.3 Haematology Health Psychology Service Annual Report: Sickle Cell Disease (Adults), Guy's and St Thomas' NHS Foundation Trust 2023-2024

(Note - full version of the report can be accessed in [Appendix 13.6](#))

9.3.1 Summary

This report summarises the sickle cell and thalassaemia specific activity for the GSTT Haematology Health Psychology Service (HPS) between 1st April 2023 and 31st March 2024.

The report focusses on 5 core service objectives:

1. Specialist psychological support for patients and significant others
2. Staff support, training and consultation
3. Promotion and improvement of psychological aspects of haematology services at a local and national level
4. Specialist trainee and student placements
5. Governance

9.3.2 Key Achievements, Current Challenges and Future Developments

Key Achievements

Successful implementation of the new GSTT electronic record system (EPIC).

Successful participation in the GSTT Haemoglobinopathies Peer Review – areas of good practice included HPS involvement of service users in recruitment to psychology posts and SCD support group.

Successful recruitment to the following: HPS is hosting a 2-year NHSE London-funded 1.0 wte 8a community psychology post which is part of a wider community pilot to invest in improvements in proactive community support to enhance quality of life and crisis prevention for patients living with sickle cell.

Despite staff shortages, HPS has continued to support a wide range of service activities in addition to regular patient appointments – these include inpatient support, MDT clinics, MDT meetings, ward handovers, transition workshops, and complex case MDMs. The team also continues to contribute to training, research and attending forums of national influence e.g. National Haemoglobinopathy Panel. The weekly sickle cell support group has continued throughout.

Current Challenges

Multiple staff changes (due to support of secondments, staff leaving for promotions and maternity leave), the resulting recruitment gaps and time taken for new relationships and caseloads to build, and the interruption in services due to introduction of the new GSTT electronic patient record system, have all contributed to long waiting times for outpatient therapy and cognitive assessment. In addition, the number of patients who are served by GSTT haematology and the outreach SCD clinics has increased since the last business case was approved (2019). This has increased pressure on remaining staff and reduced the ways in which HPS can get involved in other activities such as supporting sickle annual review clinics in person (we have switched to a phone follow up model – prioritising new patients whilst staffing is below capacity) and developing group programmes. In January 2023 the service was placed on the Haematology Risk Register (amber) due to the waiting list length and the impact of staff changes on the service. The risk was reduced in Feb 2024 but remains on the risk register while waiting lists remain lengthy.

Various actions have aimed to mitigate the risks including revision of referral criteria, opt-in initiatives, reduction in MDT clinic support, employment of a bank psychologist, and temporary increase in existing staff working hours. Current wait times for first telephone triage assessment following o/p referral for either psychological therapy or cognitive assessment has reduced from 8 to 4 weeks and the wait time has reduced to 1 year for 1-1 o/p psychological therapy

but increased to 26 months for cognitive assessment. In order to respond quickly to concerns, telephone triage assessment for o/p therapy referrals has been expanded to include risk assessment, brief interventions and signposting to self-help resources and other supportive services. Early triage of patients referred for cognitive assessment has enabled onward referral to more appropriate services and advice re coping strategies for self-reported cognitive deficits whilst waiting for detailed cognitive assessment. Recent collaboration with Kings College Hospital neuropsychology service has meant that we are currently contacting patients who are waiting for cognitive assessment to determine if they would prefer earlier assessment from that neuropsychology service with an offer of follow up feedback appointment in HPS.

The Haemoglobinopathies Peer Review Report for GSTT identified as an area of 'further consideration' the fact that psychology support for patients with SCD and thalassaemia did not meet British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia recommendation of one wte for 300 patients and is likely to be insufficient as rise in demand for the service continues. Demand for haemoglobinopathies psychology is likely to increase with the increased expectation that we provide outreach to local haemoglobinopathy services who lack their own psychology provision.

Future Developments

There is scope for expanding the service in all areas. However, given limitations to funding, our focus is on creative approaches to managing demand and ensuring a robust triage and consultation model. There is also a recognition of the need to protect more senior roles to focus on leadership, service development and overseeing complex case management.

The 8a community psychology in SCD post provides an opportunity to improve relationships with community services and signpost patients to appropriate services.

9.4 Paediatric Sickle Cell Disease & Thalassaemia Psychology Service Activity Summary, Guy's and St Thomas' NHS Foundation Trust 2023-2024

(Note - full version of the report can accessed in [Appendix 13.7](#))

9.4.1 Summary

The below information summarises the sickle cell activity for the Children's Psychological Medicine/ CAMHS Liaison Service at St Thomas's Hospital between 01.06.23 – 31.05.24. Within this time frame the service:

- Received a total of 24 referrals for individual therapeutic assessment and intervention
- Completed various ward emergency assessments when young people presented to the Evelina due to crisis pain episodes and subsequent concerns around their emotional wellbeing and/or medication compliance.
- Supported with regular transition clinics co-facilitated with the adult sickle cell psychology service based at Guys Hospital
- Provided clinical consultation as part of weekly outpatient sickle cell clinics at St Thomas' Hospital

9.4.2 Service Initiatives and Future Developments

- Continued attendance at the British Psychological Society Sickle Cell SIG
- Continued review of the Sickle Transition Clinic in order to make this a seamless and containing experience for young people transitioning to adult sickle medical teams. Transition Passports have been processed and currently being used for patients over the age of 15y.
- We hope to run a psychoeducation morning for parents with children with Pica to offer a network and support.

- We now have embedded in the Paediatric sickle cell service a transition nurse and we hope to work closely with them to develop resources for young people and have recently created a transition education booklet for all young people under our service.

10 Social work - KCH

(Note - full version of the report can be accessed in [Appendix 13.8](#))

This report details the activity of the Haematology Social Work Service at King's College Hospital from 1st May 2024 to 30th Apr 2025. This service covers both Haemato-oncology (0.5 WTE) and Haemoglobinopathy (0.5 WTE).

King's College Hospital is relatively unique in the provision of specialist social work support embedded within the haematology department. Whilst hospitals with oncology centres may have social work support available, an equivalent role across both haemato-oncology, and haemoglobinopathies is rare; social work support in any capacity in adult sickle cell services is uncommon.

A total of **230** referrals were received for social work support during the period covered by the report; further data will be presented on disease group/ referral source. 79 of these came from patients with a haemoglobinopathy diagnosis. The predominant reasons for referrals are for financial (39.2% of patients) and housing support (20.1% of patients); however support is provided for a number of issues, including arranging care support (10.3%), safeguarding (5%) and complex discharge planning (2.8%). 34% of patients were assessed as having multiple areas of need, and required support with more than one issue.

Due to the nature of the work and support provided, some patients referred in the previous year continue to receive active and ongoing support, particularly where there have been several presenting issues, or there is a high level of complexity. The data presented within this report will cover referrals received from May 2024- April 2025 only, however brief information on the cohort of patients continuing to receive ongoing social work support is provided for context.

Details of referral by source and diagnosis are described in the report, this also covers general themes of presenting issues, and training delivered.

11 SELSE Community Multidisciplinary Team Pilot

(Note - full version of the report can be accessed in [Appendix 13.9](#))

This report summarises the first 7 months of the South East London (SEL) Sickle Cell Community Pilot, which was launched to address long-standing health inequalities faced by people living with sickle cell disorder (SCD).

Taking a whole-centred approach to care, the pilot aims to meet the needs of patients of all ages by supporting them to manage their sickle cell disease and stay well through a combination of physical, mental health, and social care support. This is delivered through a partnership between three community service providers: GSTT (the hosting trust), Oxleas, and Bromley Healthcare. The pilot covers six boroughs—Bromley, Bexley, Greenwich, Lewisham, Lambeth, and Southwark.

There were 5 workstreams as listed below that the pilot sought to work towards

- Workstream 1: Expand nursing capacity within specialist community teams
- Workstream 2: Improve access to multi-disciplinary care
- Workstream 3: Enhance welfare support for patients, families, and carers
- Workstream 4: Provide peer support for children and young people
- Workstream 5: Deliver a targeted education programme

Over the 7 months, the pilot has expanded support for children and adults with SCD by increasing Community Nurse Specialists (CNS) and adding 13 WTE staff to a broader multidisciplinary team (MDT) providing equitable access across South East London. The MDT now includes a physiotherapist, pharmacist, dietitian with support from psychologists, and welfare, offering patients a more joined-up and holistic care experience.

However, the pilot also encountered key challenges, particularly with recruitment, data completeness, and variations in implementation across sites. A formal evaluation is underway, which will help shape the pilot's future direction and inform wider commissioning decisions.

The pilot has been shortlisted for the 2025 HSJ Awards, reflecting its innovative approach to reducing healthcare inequalities.

12 Conclusion and Work Plan

SELSE HCC continues to develop its services to fulfil its aims of providing best quality care for patients with Haemoglobinopathies in South East London and the South East of England.

Our 6 key objectives for 2025/2026 are to:

1. Improve communication and co-ordination throughout the network, including identifying key stakeholders and agreeing SLAs with all of our LHTs
2. Improve Urgent and Emergency Department care and pathways.
 - a. Initiate L&G Hyperacute pathway and assess outcomes
 - b. Share acute sickle management e-learning across all the LHTs and SHTs in our network
 - c. At GSTT and KCH - continue to promote and increase uptake of e-learning and embed as part of mandatory learning
3. Establish and increase availability and equitable access to apheresis (red cell exchange) at all SHTs
 - a. Explore options for apheresis service at CUH
 - b. Increase apheresis availability at KCH, UHL and GSTT
 - c. Explore an out of hours plan which covers our whole network (including LHTs)
4. Increase patient engagement and involvement across the network including exploring patient representation at SELSE HCC business meetings.
5. Continue to work with the ICB team to establish enhanced community provision including specialist psychology, benefits and housing support, CNS, dietician, physiotherapy, and pharmacy.
6. Improve data collection and monitoring throughout the network

13 Appendix

13.1 Network Education Event (Nov 24) – Agenda

1500: Welcome – Dr Samah Babiker

1505: Network Pain audit results and discussion (learning from good practice and how do we involve our DGHs?) – also plans for next network Audit – Dr Samah Babiker

1540: Royal Sussex County Hospital Parvo case – Dr Elaina Pasangha SpR (and Dr Tom Rider)

1600: KCH/QEH Paeds parvo case Dr Daniel Dexter (SpR)

1615: Parvovirus case series at KCH Dr Sumitha Pandiaraja SpR (and Dr John Brewin)

1630: Parvovirus in SCD - Dr Zuckerman

1700-1730: Q+A and Close Dr R Kesse-Adu

13.2 PREMS (2023) – GSTT Results and Actions Arising

Problematic areas; 9 categories where >50% patients had a 'problem' with the issue.

Did the emergency HCP know enough about SCD?

- Implemented e-learning in 2024 have had >1100 staff complete it
- Recent survey of staff confirmed it impacted on attitude of staff
- Ongoing nursing teaching via sickle nurses and ED sickle-link nurses – including medical and psychological aspects
- Ongoing medical teaching

Did the emergency staff help ease your pain?

- Elearning implemented and is compulsory for senior staff but has been completed by large number
- Epic analgesia plans Oct 2023
- UCP implementation completed July 2024
- 4 Link nurses in ED from 2024
- Regular teaching for MDT

Was the ward that you stayed on suitable for your age?

- We have two new wards since the PREMS and an area suitable for younger patients but we do still have a high number of outliers
- Ensure regular teaching to nurses on all wards the SCD patients are admitted to

Were there enough doctors and nurses on duty in the wards

- Likely to be intermittently ongoing as staffing throughout the NHS is problematic – but do still intermittently have wards that have bank nurses this is much improved from 2023

Do healthcare staff give enough information to others

- We have ongoing regular sickle-nurse and psychology teaching to all wards that have SCD patients
- Regular regional and inhouse nurse training days and also teaching to ED team
- SCD Trust website for leaflets

Do you get info re different Rx options

- Created QR codes for patient information leaflets and also have hard copies to post out. Can also append to clinic letters
- Discuss research opportunities in OPA

Do you get a chance to meet others with SCD for support

- Regular weekly support group and now have a young persons group
- Peer mentoring program for under 25s via sickle cell society

Do you have to repeat your story to members of staff

- Ensuring only salient points of the history are confirmed when transferred from STH ED to Guys

Overall, how do you think staff look after your condition

- Hopefully all of the above actions will result in improved reporting

Psychology Service actions:

Did you get a chance to see a psychologist or a counsellor

- We have started being more present during Tuesday clinics and making sure and prioritising patients and families who we haven't met before
- We also have planned to meet with patient and their parents, who have their annual TCD scan, to offer and do an annual more thorough screening for potential cognitive and/o learning difficulties as well as emotional well-being.

- With the caveat that the regularity and consistency of this depends highly on clinic room availability. It would be important to work around having access to a clinic room, for this improvement to be embedded robustly.

Do you have enough info re support groups:

- For the support group we and CNS's run, we are responsible about advertising and making this known.
 - We advertise by emailing to our emailing list of approximately 130 parents who have consented to give us their email address and send communications.
 - We advertise at the reception areas: there is a laminated poster at the reception area.
 - CNS puts a copy of the poster in the pack of leaflets and information given to the parents.
 - The poster is sent out by post as well with clinic letter.

Results:

Theme: Specialist		n
HCP enough knowledge re SCD	28%	81
Did HCP talk to you in a way that you could understand	15%	81
Did HCP answer your questions clearly	38%	58
Were HCP sympathetic and understanding	35%	79
Theme: Emergency		
Did the emergency HCP know enough about SCD	69%	35
Were the emergency HCP sympathetic and understanding	46%	35
Did the emergency staff help ease your pain	65%	34
Theme: Ward		
Was the ward that you stayed on suitable for your age	62%	45
Were there enough doctors and nurses on duty	63%	48
Theme: Information		
Do you have enough information about your sickle cell	29%	92
Do healthcare staff give enough information to others	72%	47
Do you get info re different Rx options	75%	80
Are you involved enough in decisions re Rx	50%	90
Do you have enough information about your meds	21%	86
Do you have enough infor re coping with pain	29%	92
Do your friends and co-workers know enough re SCD		
Theme: support		
Do you have enough info re support groups		
Do you get a chance to meet others with SCD for support	53%	55
Have you been offered counselling or psychology	10%	83
Do you have to repeat your story to members of staff	67%	48

Overall how do you think staff look after your condition	57%	91
Problem score Above 50	10	53%
Problem score Between 25 and 50	6	32%
Problem score Below 25	3	16%

13.3 PREMS (2023) – KCH Results and Actions Arising

Analysis of 57 responses received from KCH adult patients in 2023 HCC-wide PREM survey. Questions covered 4 wide themes: Specialist, Emergency, Ward, and Information/support. Problem scores were calculated problem for each question. This means for the question ‘HCP enough knowledge re SCD’- only 24% had a problem with it, meaning 76% respondents felt that HCP were knowledgeable re SCD.

9 categories where >50% patients had a ‘problem’:

- 1) **Did the emergency HCP know enough about SCD?**
- 2) **Did the emergency staff help ease your pain?**
- 3) Were there enough doctors and nurses on duty in the wards?
- 4) Do healthcare staff give enough information to others?
- 5) **Do you get info re different Rx options?**
- 6) **Do you get a chance to meet others with SCD for support?**
- 7) **Have you been offered counselling or psychology?**
- 8) Do you have to repeat your story to members of staff?
- 9) Overall, how do you think staff look after your condition?

We selected five problem areas and used these as the basis for quality improvement measures to embedded in our routine services as a result of patient reported experience from the 2023 PREMS:

1. Did the emergency HCP know enough about SCD?

We improved ED staff knowledge about sickle cell disease by the following actions:

- 1) 12 Bitesize teaching sessions delivered I the Emergency Department per year
- 2) 6 monthly 1.5 hour sessions for ED juniors per year
- 3) Campaign for e-learning module to be mandated for all ED staff
- 4) Enamelled metal sickle badges for those who have completed training

2. Did the emergency staff help ease your pain?

We planned to improve time to analgesia and appropriateness of analgesia by:

- 1) Implementing Universal Care Plan – implemented March 2024, now >90% complete
- 2) Implement and maintain updated Epic sickle alert and Epic Care Plan pops ups
- 3) ED training as above
- 4) ACT NOW launch as a pilot site 21st May 2024, now embedded in routine teaching

3. Do you get information re different Rx options?

We improved patient access to information about different available treatments by:

- 1) Production of a leaflet outlining treatment options
- 2) HCC illustrated hydroxycarbamide leaflet inserted into clinic letters by Epic short code
- 3) Gene Therapy information leaflet produced in February 2025, after January 2025 NHS approval of funding for Gene Therapy in selected cases, appended to letters of interested & eligible patients

4. Do you get a chance to meet others with SCD for support?

- 1) We re-launched patient support group which is now run by patients and supported by CNSs, meeting regularly face to face or virtually
- 2) Regular face to face transition workshops for 16-19 year olds

5. Have you been offered counselling or psychology?

We improved access to psychology by:

- 1) Successfully recruiting an additional full time psychologist
- 2) Referral of patients to Enhanced Community team monthly online psychology workshops

Results:

Question	Problem Score Low is good!	n = 57
Theme: Specialist		
HCP enough knowledge re SCD	24%	46
Did HCP talk to you in a way that you could understand	19%	47
Did HCP answer your questions clearly	34%	41
Were HCP sympathetic and understanding	32%	47
Theme: Emergency		
Did the emergency HCP know enough about SCD	59%	37
Were the emergency HCP sympathetic and understanding	44%	36
Did the emergency staff help ease your pain	63%	35
Theme: Ward		
Was the ward that you stayed on suitable for your age	37%	35
Were there enough doctors and nurses on duty	63%	38
Theme: Information		
Do you have enough information about your sickle cell	28%	57
Do healthcare staff give enough information to others	56%	36
Do you get info re different Rx options	65%	54
Are you involved enough in decisions re Rx	40%	55
Do you have enough information about your meds	18%	55
Do you have enough info re coping with pain	38%	56
Do your friends and co-workers know enough re SCD		
Theme: support		
Do you have enough info re support groups		
Do you get a chance to meet others with SCD for support	62%	42
Have you been offered counselling or psychology	58%	45
Do you have to repeat your story to members of staff	79%	56

Overall how do you think staff look after your condition	57%	56
Above 50	9	47%
Between 25 and 50	7	37%
Below 25	3	16%
Number of questions w/answers	19	

13.4 Psychology Service for Adults with Sickle Cell & Thalassaemia, King’s College Hospital NHS Foundation Trust Annual Report 2023-2024 – Report Detail

13.4.1 Service Structure

The service is staffed as follows

- Band 8a Lead Psychologist (0.8wte) vacant since November 2023
- Band 7 Psychologist (1wte) in post since July 2023
- Honorary Assistant Psychologist contract to December 2025

13.4.2 Current Challenges

As highlighted in previous annual reports, service demand has continued to grow while staffing levels remain below the one full-time psychologist per 300 patients (1:300) recommended by the British Psychology Society’s special interest group (SIG) for psychologists working with sickle cell and thalassaemia. At the time of writing, there are 878 active adult patients with a haemoglobinopathy registered at King’s. With the current staff in post (1wte B7), this equates to 1:878 and if fully staffed, this equates to 1:488. Similar sized services in the area function with several psychologists.

The lack of desk and clinical space is an ongoing, significant, and disruptive issue which impacts service delivery and job satisfaction. Availability of a bookable area on Derek Mitchell Unit (DMU) has eased clinical space issues in the short term while a substantial long-term solution is sought by the department. The service with 1wte B7 currently operates as follows:

<i>day</i>	<i>session</i>	<i>service</i>	<i>location</i>
<i>Monday</i>	AM	Virtual clinic	WFH
	PM	Virtual clinic	WFH
<i>Tuesday</i>	AM	Hybrid clinic	IT chemotherapy room, DMU
	PM	Virtual clinic	Pod, Caldecott Centre
<i>Wednesday</i>	AM	Hybrid clinic	IT chemotherapy room, DMU
	PM	Hybrid clinic	IT chemotherapy room, DMU
<i>Thursday</i>	AM	Clinical/ non-clinical admin	Office
	PM	Hybrid clinic	Haematology Outpatients

HCC

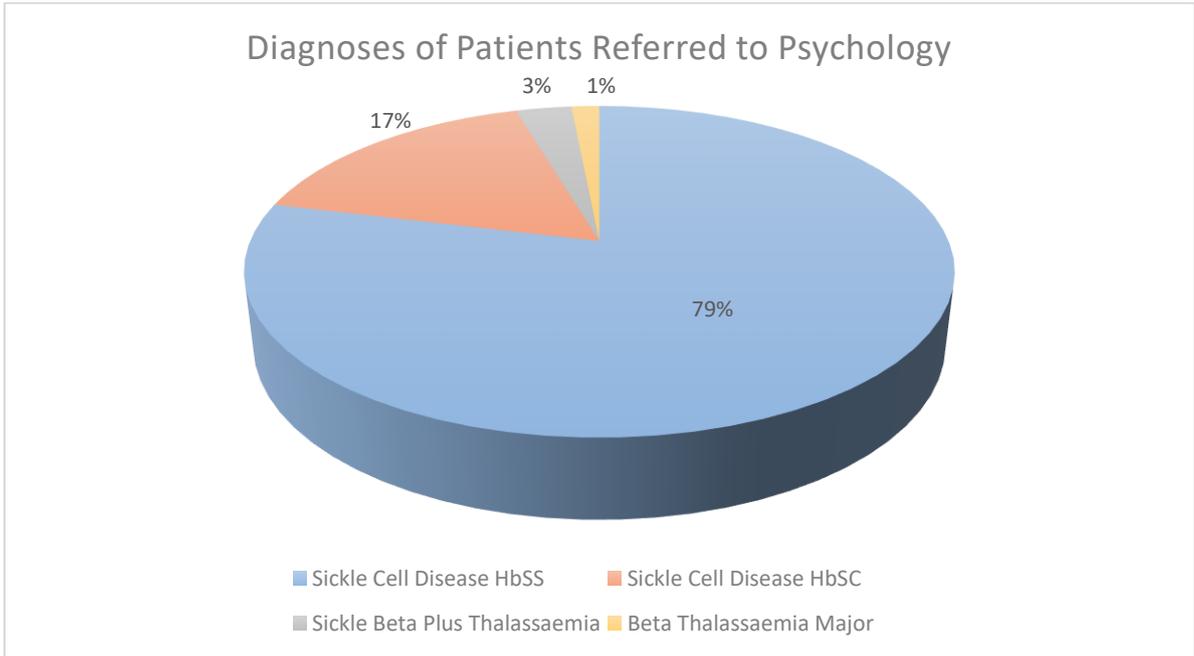
South East London and South East

Friday	AM	Clinical/ non-clinical admin	Office
	PM	Hybrid clinic	Haematology Outpatients

The ongoing desk and clinical space issues will be further pronounced once the service is fully staffed as there is no current space provision for a 2nd psychologist. There is a significant need to establish permanent and adequate facilities within the department to offer and deliver mental health services. Appropriate clinical space – for either in person appointments or remote work – must be characterised by privacy and quiet to create a safe environment for the patients and to abide by the professional and ethical code of practice and conduct.

13.4.3 Service provision

The psychology service provides both inpatient and outpatient support to people with haemoglobinopathies living in South London and Southeast England. The service accepts referrals from patients suffering from any haemoglobinopathy condition. However, the vast majority of patients seen have sickle cell disease. The distribution of diagnoses for patients referred to the service this year can be seen in the chart below.



Psychologists join the consultant-led haemoglobinopathies ward round, attend multidisciplinary team meetings, and provide psychological support and input to patients, at times working in collaboration with other services, such as liaison psychiatry and social services.

Inpatients who meet with the psychologists are offered the option of accessing the service as outpatients and receive the psychology service leaflet.

Referrals can be made by any professional within the Haemoglobinopathy - e.g., consultants, nurses, social worker, GP, etc. - or by the patients themselves. The distribution of referral sources can be seen in the chart below.

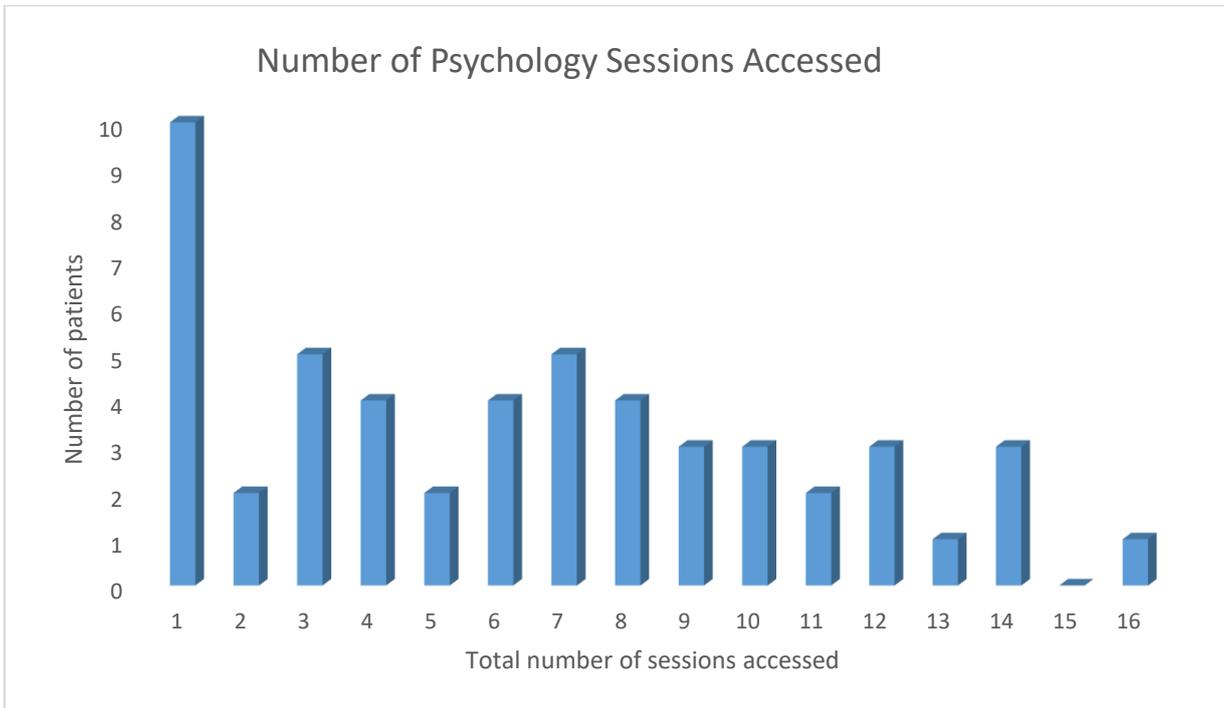


With the introduction of the EPIC electronic health records system, the service has implemented an electronic referral process that has been live since 2024 with the majority of referrals generated by members of the haemoglobinopathies team. However, some referrals are still generated through outpatient clinic introductions or during hospital admission.

As this is a highly specialist service with limited capacity, staff are encouraged only to make referrals for patients whose psychological needs are closely related to their medical condition. All patients are routinely given a copy of the psychology service leaflet, however, and are able to contact the service themselves to self-refer and book in an appointment.

Therapeutic intervention draws on the present psychologists' expertise, and currently uses Cognitive Behavioural Therapy (CBT), Acceptance and Commitment Therapy (ACT), Compassion Focussed Therapy (CFT) and Psychodynamic Psychotherapy.

Patients are offered 6-12 sessions as standard, with the offer to extend to a maximum of 20 if clinically indicated. The median number of sessions accessed was 6 and the mean was 6.38. The range was 1-16 sessions. Information on the number of sessions accessed can be seen in the graph below.



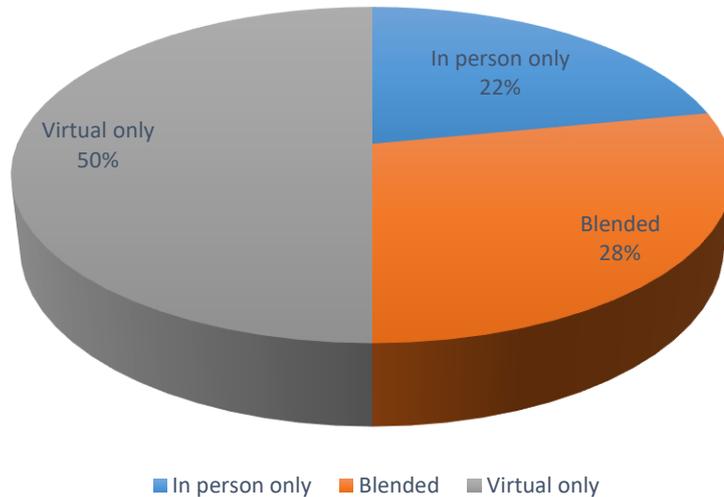
Decisions on which patients to prioritise are made through assessing them and through collaboration with the rest of the haemoglobinopathies team. The service offers a stepped-care approach in order to make a clinical decision on what type of treatment or signposting option is the most appropriate.

A scheduled screening, assessment, psychology session or follow-up appointment in one of the following formats is offered:

- In person
- Video conference (via Microsoft Teams)
- Telephone
- In person inpatients support or screening for patients admitted to hospital
- In person screening within outpatient clinic
- Telephone screening

For ongoing sessions, patients are given the choice between remote appointments or in person appointments at KCH. They can also blend both options to suit their current state of health and level of mobility. A breakdown of patients' primary preference is demonstrated in the pie chart below.

Modes of Accessing Psychological Support



Patients requiring psychological that does not fall within the service criteria are signposted and referred to other services as appropriate.

13.4.4 Multidisciplinary clinics

The adult psychology team participated in the following MDT clinics

The Haemoglobinopathies Outpatient Clinic (weekly)

During this clinic, the service has seen patients for scheduled psychology outpatient appointments or for an ad hoc screening or assessment after a patient had attended an outpatient appointment and had been introduced to them by a member of the adult haemoglobinopathies team.

The Transition Clinic (monthly)

The B7 psychologist is present at these monthly clinics in collaboration with one of the psychologists of the Paediatrics Sickle Cell & Thalassaemia team. Adult and paediatric psychologists meet with all young patients, introduce the psychology provision and briefly assess the patient’s psychological wellbeing, leading to a referral if necessary.

Patient Support Group

A patient support group is convened monthly by other members of the haemoglobinopathies team and will be supported by psychology when staffing permits.

13.5 The Children and Young People’s Sickle Cell & Thalassaemia Clinical Psychology Service, King’s College Hospital NHS Foundation Trust Annual Report 2023-2024 – Report Detail

13.5.1 Background

The Children & Young People’s Sickle Cell & Thalassaemia Clinical Psychology Service forms part of the National & Specialist Paediatric Liaison Service within South London & Maudsley NHS Foundation Trust. The service aims to work in partnership with members of the Paediatric Haematology multi-disciplinary team based at Kings College Hospital to deliver holistic and coordinated care to children and young people with sickle cell anaemia and/or thalassaemia, and their families, and provide psychosocial and neuropsychological assessment, intervention and support through direct

casework, consultancy, training, audit and research. This service covers the patients of King's College Hospital as well as the patients of the hospitals in the South Thames Network where the Kings Paediatric Haematology Consultants offer out-reach clinics.

13.5.2 Service Structure

Between May 2019 and January 2020, there was no Clinical Psychology support for patients under The Children & Young People's Sickle Cell & Thalassaemia Clinical Psychology Service, as the post was vacant. A new Clinical Psychologist was appointed in middle January 2020, and began accepting referrals in February 2020. In October 2021 a second clinical Psychologist was recruited. The service is currently comprised of:

- Maria Goridari (1.0 wte, Band 8a) &
- Dr Stacey Barkley (1.0 wte, Band 7)

13.5.3 Current Challenges

- The patients who we see have been presenting with more complex difficulties needing more psychosocial support and not just psychological. Socio economic factors and other social, environmental and familial factors contributing to the complexity of their presenting difficulties.
- Hybrid model is implemented and continued offering in person and online therapeutic work and professional meetings.
- Paediatric Psychology Team at King's College Hospital has been expanding creating difficulties with desk space and therapy room space which have not expanded proportionally. It is very hard to find appropriate therapeutic space for groups for young people and children as well sufficient therapy space to facilitate individual sessions.
- The above more time than not, dictate whether the psychological intervention will be offered in person or online as well as creating various other limitations as well.
- The above create unnecessary anxiety to the clinicians as well as additional pressures on planning and admin work. Inefficient use of time needed to travel to and from work in order to be able to do online work.
- Experienced technological difficulties in relation to stable internet connection, good speed of internet connection etc.
- Virtual/ remote clinical input has made it an added challenge to develop a therapeutic rapport with some young people who are ambivalent about engaging in therapy in the first instance.
- Difficulty to consistently administer and monitor therapeutic techniques online.
- Referrals have increased; both for neuro psychological assessments (as it is part of the standard care for sickle cell and thalassaemia patients) and for individual psychological assessment and intervention. Group work has started as well. This creates the need for space and therapy room which is not enough and appropriate. Work load is increasing and there may be a need to start a longer waiting list.
- Clinical work occupies the majority of the clinicians time, to meet the patients needs leading to less time for research and further, innovative service development.
- Psychology service being under a different Trust may lead to confusion, more complex and sometimes double in time and effort processes, leading to delays and friction.
- No funding or budget for expenses ready and easy to use (i.e. materials and lunch for Tree of Life group for young people and children), without clinicians having to pay from their pocket and claiming expenses back.
- It has been a challenge to recruit parents, young people and children for group work. This challenge is shared with other services as well. A combined difficulty of advertising and taking up of/committing to the offer for group work.

Consideration is required to ensure that clinical need continues to be met with the less impact on service efficiency and efficacy.

13.5.4 Direct Clinical Work

A total of 60 new referrals were received by the service between April 2023 and March 2024. The age range: 3 years – 17years.

- Fourteen (13) referrals were for a neuro-psychological assessment.
- Twenty four (31) referrals were for psychological intervention.
- Fourteen (12) referrals for group work and
- Four (4) for Consultation Provision to schools.

In addition to the new referrals, there were already ongoing, long term treatments and neuro psychological assessment referrals on the waiting list.

Reasons for referral for psychological intervention - presenting problems;

- Pica symptoms (8 referrals)
- Procedural anxiety - needle phobia (7 referrals)
- anxiety and low mood related difficulties (7 referrals)
- Adjustment and coping with health condition (2 referrals)
- Frequent pain and pain management (6 referrals)
- Adherence (0 referrals)
- Tree of Life Group (3 referrals)
- Parents in Mind Group (12 referrals)
- Neuropsychological Assessments (13 referrals)
- Consultation to schools (4 referrals)
- Ward Emergency (1 referral)

Location/CCG;

- Croydon, 15 referrals
- Southwark, 13 referrals
- Lambeth, 7 referrals
- Bromley, 5 referrals
- Lewisham, 4 referrals
- Kent, 4 referrals
- Bexley, 3 referrals
- Greenwich, 3 referrals
- Liverpool, 2 referrals
- Sutton, 1 referral
- Waltham Forrest, 1 referral
- Surrey, 1 referral

The patients who we see have been presenting with more complex difficulties needing more psychosocial support and not just psychological. Socio economic factors and other social, environmental and familial factors contributing to the complexity of their presenting difficulties.

13.5.5 Multidisciplinary Clinics

Psychology is present or available in each clinic for:

- Sickle Cell Clinic (Weekly)
- Nurse Led Clinic (Weekly)- Paused at the moment
- Transfusion Clinic (Monthly)

- Transition Clinic (Monthly)
- Haemoglobinopathy MDT (Monthly)
- Combined neurology/sickle cell clinic (Bi-monthly)
- National Haemoglobinopathies Panel

In addition:

- Maria Goridari and Dr Stacey Barkley, facilitate a monthly psychology consultation multidisciplinary meeting, the aim of which is to provide opportunity for the team to discuss the psychosocial needs of specific children and young people under the care of the paediatric haematology service and to develop a shared plan of how these young people may be best supported.
- Maria Goridari and Dr Stacey Barkley, facilitate a monthly (at the moment) reflective session for the clinical nurse specialists.

13.5.6 Teaching and Training

- 1) “Clinical Psychology in Paediatrics”, 3 hours class to 1st Year students of Doctorate in Clinical Psychology at IoPPN. It is scheduled to occur again in June 2022. Maria Goridari, alongside Dr Fay Coster, Clinical Psychologist at King’s College Hospital for the Cystic Fibrosis and Asthma Departments, provided and will provide again this teaching.
- 2) “Effects of Sickle Cell Disease on children’s education- Lewisham SENCO’s network and Local Authority Educational Services”, 2 separate sessions of an hour and a half presentation and discussion of sickle cell and its impact on learning and education.
- 3) Teaching to Pre and Post Registration Nursing Course. “The Psychological impact of living with a haemoglobinopathy-sickle cell & thalassaemia”. Joined teaching session with Senior Clinical Nurse Specialist. 1hour and 2 hours teaching sessions respectively.
- 4) Bite size teaching in ED, re psychological aspects of SC

13.6 [Haematology Psychology Service \(HPS\) Annual Report; Sickle Cell Disorders and Thalassaemia \(Adults\) -GSTT – Full Report](#)



SCD HCC GSTT
Haematology Health

13.7 [Paediatric Sickle Cell Disease & Thalassaemia Psychology Service Activity Summary \(GSTT\) – Report Detail](#)

13.7.1 Background - Service Structure

The CAMHS Paediatric Liaison service at St. Thomas’s Hospital forms part of the National & Specialist Paediatric Liaison Service within South London & Maudsley NHS Foundation Trust. The service includes one clinical specialist and one highly specialist Psychology post who provides clinical consultation and direct clinical assessment/intervention to the paediatric sickle cell and thalassaemia team at the Evelina Children’s Hospital over a total of 5 days per week. This service aims to work in partnership with members of the Paediatric Haematology multi-disciplinary team based at the Evelina within St Thomas’s Hospital to deliver holistic and coordinated care to children and young people with sickle cell anaemia and/or thalassaemia, and their families,

and provide psychosocial assessment, intervention and support through direct casework, consultancy, audit and research.

Referrals are sent to us from the whole of the sickle cell team- consultant, clinical nurse specialist, community nurse. We also received referral from the General Paediatric wards at the Evelina. We are currently funded to see all children and young people from Southwark and Lambeth. However, we need to apply for funding for children and young people outside of these boroughs for outpatient input.

Therapeutic support is currently provided by both Dr Hatel Bhatt Clinical Specialist/ Counselling Psychologist and Sarah Brennan Clinical Specialist/ Senior Occupational Therapist. Dr Hatel Bhat went on maternity leave Sept 2022 and Sarah Brennan went on maternity leave Jun 2023

13.7.2 Current Challenges

- Between June 2023 and November 23, both full time permanent members of staff (one band 7 and one band 8A) were on maternity leave, and unfortunately, we only had one band 7 MH CNS to cover this.
- Post Covid impact: There has been an increase in mental health associated difficulties as schools, families and young people are now identifying some of the post covid difficulties. Young people have described worries about managing school and
- education with an expectation to now be back to 'normal', however young people are feeling worried about 'catching up', reporting anxiety related to not having educational and emotional needs met during lockdown and restrictions. This increase has led to more school and liaison with education services and more referrals to our service.
- Increase in complex health and mental health cases being referred and increase in safeguarding concerns.
- Our members of the team do a split role and so we do not cover one full time equivalent post. This initiates restrictions and constraints in what we can offer the team.

13.7.3 Positive Steps and Changes

- We have now begun face to face appointments since this was put on hold as per COVID regulations. This change has seen an increase in engagement in therapy sessions.
- We are still yet to get consent from the trust regarding school meetings and outreach work- however, this has just changed, and we are now conducting community input.
- Two permanent members were on maternity leave, with one returning November 23. This has meant, since November 23, there have been two members of staff now providing one full time equivalent input again for the Paediatric sickle cell team.
- We continue to provide robust input both through out-patient and emergency capacity, on the hospital ward and in clinic.
- Tighter and more streamline policy in place for funding to be improved. This has meant cases are now funded easily, allowing reduced waiting times from referral received.
- Closer working with Evelina Neurodevelopmental service to allow streamline service for referrals.
- We began the start of our Sickle cell coffee morning group- which we intend to run one per month.
- We held a transition workshop in February 2024
- Initiated changes to transition clinic and role of psychology.
- Positive outcome and comments noted regarding psychology input for the service in our latest peer review.

13.7.4 Direct Clinical Work

A total of 24 referrals were received. This was a decrease from 33 referrals in comparison to the same timeframe between 2021/2022. One of the reasons for the decrease in referrals were due to changes in staffing levels. It is also important to note that the maternity role has split duties in Paediatric sickle cell as well as CAMHS Liaison.

We have seen a big increase in referral related to PICA and assessment for neurodevelopmental difficulties. This is in part due to the PICA trial being facilitated by the Paediatric sickle cell team.

In addition, we have also observed a great rise in the overall number of cases under the Paediatric service that are now open to social care. This has had a direct impact on referrals that are complex and currently under child in need or child protection plans. It has meant that our role has had an increase in the role of liaison with externals services and clinical work being contributed to MDT meetings and complex case discussions. In response tot his rise, we have become more aware of record keeping over both SLAM AND EPIC systems and our communication has been tighter and more effective in liaison with the Paediatric sickle cell team.

Children and young people were referred to the service for a variety of reasons including assessment and intervention in relation to pain management, school related stressors, depressive and anxious symptomatology associated with living with a chronic medical condition and pica behaviours. All referrals comprised of children & young

People, with many referrals being from Lambeth or Southwark catchment areas.

We have also successful began a once-a-month coffe morning for parents. Each moth covers a topic, the first being held in June 2024 covering pain management.

13.7.5 Multidisciplinary Clinics

Psychology is present or available in each clinic for:

- Sickle Cell Clinic (Weekly)
- Transition Clinic (Monthly)
- Haemoglobinopathy MDT (Monthly)

We facilitate a psycho-social and complex case discussion joint with the paediatric sickle cell and Neuropsychologist once a month.

Neuropsychology input:

Our service do not offer any neuropsychology assessment and so these referrals are redirected to the neuropsychology team at the Evelina. We may be requested from the Neuropsychology team to support recommendations made from their assessment, liaison with school and for further formal assessments of their mental health.

13.7.6 Liaison with children social services:

We have had an increase in liaison with children social services for our patient group. This has ranged from early help intervention to families that have shared they are struggling for acute safeguarding concerns.

13.7.7 Transition pathway:

We play a role in the transition process for young peoples' move to adult services. We currently attend a transition clinic once a month. Our role extends to also supporting young people to engage with adult psychology team and facilitating joint assessments.

We are currently working on updating our resources for young people and working to further integrate the role of therapy into this process to better support young people.

13.7.8 Other contributions from the team:

Anike Oladejo has just started in the paediatric Liaison Service at St. Thomas, covering the role of Sarah Brennan. Due to Anike having just started in the role, information about other contributions of the team in the past year is not available.

13.8 Social Work Service – Dept of Haematology – KCH - Full Annual Report



Haem Social Work
Annual Report 2023

13.9 SE London Sickle Cell Community Multidisciplinary Team Pilot – 7-mth summary report (Oct 24-May 25)



SEL_Sickle_Cell_Community_Pilot_Repo