HCC SOUTH EAST LONDON & SOUTH EAST ANNUAL REPORT

2023-2024

HCC

South East London and South East

Table of Contents

1 Introduction

This annual report covers the period April 1st 2023 to March 31st 2024, but was delayed in preparation and publication because of issues across the network including long-term leave of both SELSE HCC administrative/management staff; Synnovis pathology ransomware cyber-attack which caused massive disruption to services within our network throughout June until early November 2024; intermittent NHS staff strike action; a national blood shortage; launch of a new patient electronic health record system, Epic, on 5 October 2023 at several large London hospitals including Guy's and St. Thomas's Hospital, Evelina Children's Hospital, and King's College Hospital; additional non-clinical activity required for our network-wide Peer Review at the beginning of 2023; compounded by a significantly understaffed service.

Despite these challenges, the South East London and South East Haemoglobinopathy Coordinating Centre (SELSE HCC) worked hard to provide high quality specialist care for patients with haemoglobinopathies, received constructive and encouraging Peer Review reports, managed an expanded research portfolio including novel therapeutic agents mitapivat and etavopivat, and increased access to cutting edge treatment such as curative reduced intensity fully matched sibling stem cell transplant, and the REDRESS study of haploidentical stem cell transplant in adults.

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. A total of 17 patients have received transplants and the procedure has been successful in 14, with graft rejection occurring in three individuals. The REDRESS trial of haploidentical stem cell transplants in adults with sickle cell disease was launched on Saturday 20th May 2023, and in our network 6 patients have been randomised and 1 patient has had a successful transplant. Four patients were randomised to best supportive care so were not eligible for a stem cell transplant, and the other transplant was delayed for patient personal reasons.

Nationally, it has been a difficult year for SCD, with Crizanlizumab being licensed in the UK in 2021, receiving NICE approval in November 2021, as the first new drug in SCD for 30 years and was widely rolled out to patients, including across our network. Services to administer Crizanlizumab were developed across the network, including a multidisciplinary approval process, patient information and drug administration. On January 10th 2024, the Crizanlizumab licence was revoked by the Medicines and Healthcare products Regulatory Agency (MHRA).

Access to Voxelotor, another new SCD treatment, became available via the Early Access to Medicines Scheme (EAMS) in October 2022, and a small number of eligible patients in our network began to have access to this medication. In May 2024, Voxelotor was approved by NICE and became available for NHS prescription and number on treatment further increased. In September 20204 the drug company producing Voxelotor, Pfizer, abruptly withdrew Voxelotor from the market due to "an imbalance in vast-occlusive crises and fatal events which require further assessment". This medication was therefore unavailable with immediate effect.

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. We continue to work as a network to ensure that issues raised within this report have been addressed throughout the network. Significant improvements to the care of those with sickle cell disease have been achieved, facilitated by the launch of a shared electronic patient record software '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 care plans, facility to automatically real-time flag all sickle inpatients to the relevant teams, and facilitate accurate audit of time from presentation to the first dose of opiate pain relief.

We launched our in-house co-produced e-learning educational module in November 2023 which is being mandated for completion by all patient-facing staff in the Emergency Department, Haematology and Paediatric departments at

Guy's 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, Croydon University Hospital planned, and the module is being made freely available to any other interested Trusts, with the expectation that this will eventually be compulsory for all hospital staff across the network.

NHS England provided significant funds to set up an Enhanced Community Service within the South East London area, building on existing community services at Wooden Spoon House (Elephant and Castle) and focussing on long-term community support with enhanced benefits and housing officers, psychology, legal assistance, education and self-management, peer support and community connectors, social prescribing, as well as access to specialist dietetics, pharmacy and physiotherapy. These services were rapidly expanded during this financial year, including recruitment, orientation and education of large numbers of new staff, managing safe sharing of information and working across different electronic patient records. The service is now functioning at 100% capacity.

As a network we continue to provide regular network sickle cell disease awareness and education to patient groups, staff and nurses and doctors in training, including being involved in the development and launch of the sickle acronym "ACT NOW".

We repeated the Patient Reported Experience Measure in Sickle Cell Disease (PREMS) in 2023, and findings were sent to all the Specialist Haemoglobinopathy Teams in the network. Simple infographics were prepared to display in poster form in clinical areas for patients and staff and each Trust began work on measures to improve areas of poor performance highlighted by the PREMs reports.

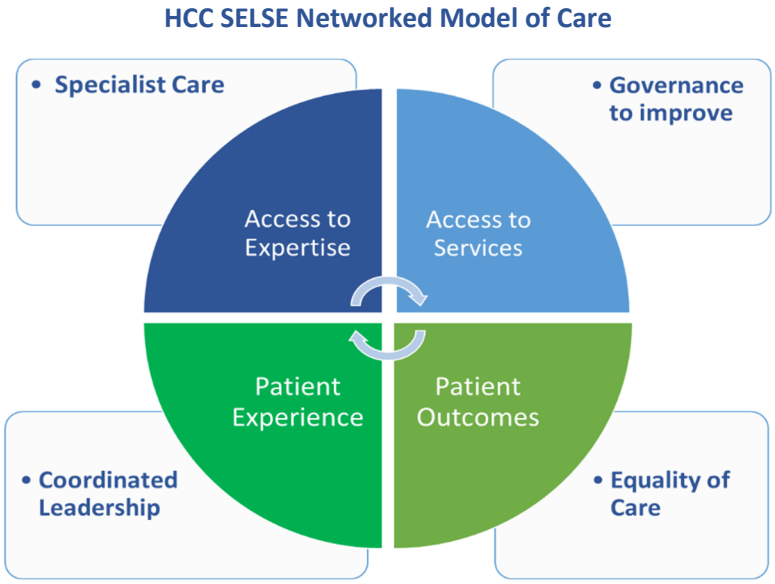
Many thanks to the staff across the HCC who have contributed to this report and worked so hard during 2023/24.

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. During the events of the past year, the NHP has established itself as a national platform, providing a forum to agree and communicate upon matters impacting haemoglobinopathy patients across the country.

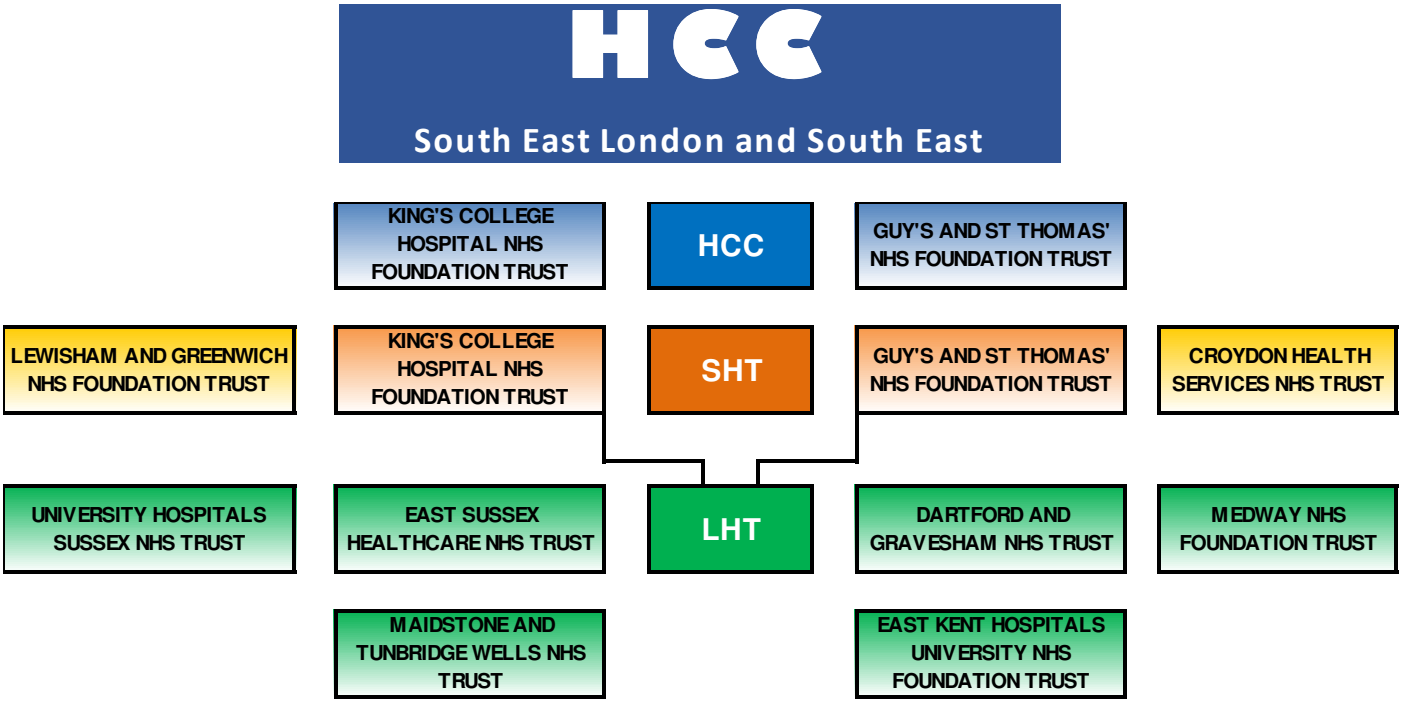


3 HCC Framework

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 Hosptial (KCH)
Deputy Lead	Dr Rachel Kesse-Adu	Guy's and St Thomas' Hospital (GSTT)
Network Manager	Maria Omosore	KCH/GSTT
Network Aministrator	Daud Daud	KCH/GSTT
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 Grennwich NHS Trust (L&G)
Paediatric Guidelines:	Samah Babiker/ John Brewin/ Sarah Wilkinson	GSTT; L&G
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

4 Operational Meetings

We have a number of meetings to ensure smooth running of the HCC. These are as follows:

HCC Strategy meetings: held monthly and attended by KHP consultants and the HCC management team

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 Delivery meetings: held quarterly and attended by multidisciplinary teams from all four SELSE SHTs and the HCC management team.

HCC Network meeting: To be held twice a year. Each site within the HCC had the opportunity to summarise current achievements and challenges in their service and receive feedback/advice where appropriate.

Finally, the HCC Chair and HCC Manager meet weekly 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 2023-24, as we adopted new ways of working to deliver education and training.

5.1 Peer Education Meetings

5.2 Nurse led Education

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

This years teaching was aimed at nursing and allied health professionals, patients and the general public. Nursing and Allied Health professional education is focused on addressing issues raised by the no one is listening event and the HCC's own patient feedback. Whilst patient education was focuses on empowering patient with the latest knowledge and therapy development to help enable true partnership between patients and clinicians. Whilst education of the general public was aimed at raising basic awareness of sickle cell in an attempt to reduce the stigma that patient experienced by Sickle Cell patients.

Nurse and Allied Health Professional Education – Focused on pockets of the SELSE HCC which currently have less opportunities to attend training sessions. This has been achieved by orgainising training in collaboration with our KHP partners and opening individual trusts training days to all nurses in the network. In addition to this the teams provide mini bite size teaching on Sickle Cell to colleagues and members of the public with the support of the trusts patient support group.

- GSTT Led – 17 July 2024
- GSTT Led – 19 February 2024
- KHP/HCC Study Day GSTT and KCH Led - 5 July 2023
- KHP Haematology Conference 24 June 2024
- Sickle Cell Awareness Month September 2023 (engagement events piloted at KCH)
- Sickle Cell Awareness Day 19 June 2023

In addition to the above the SELSE HCC also collaborated with trust **Staff Network and the EDI teams** to raise awareness among staff by holding stalls at Staff Networks and EDI events.

- REACH Network conferences 28 September 2023
- Black History Month Celebrations October 2023

This approach was piloted at KCH in 2023 and are pleased to share that we have started working on a similar partnership with GSTT and have plans to expand further during 2024/2025.

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 March 2024and are due to present at this year's KHP conference and will be attending ASCAT later on this year.

Patient 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 attendants.

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 October 2023
- Croydon BME Forum — 12 March 2024
- ARC South London Knowledge Exchange — 19 March 2024
- Clinical Research Network Sickle Cell Event — 18 May 2024
- Inspire London – Peckham — 25 May 2024
- Lambeth Black Health event — 6 July 2024
- Croydon Sickle Cell Support Group Annual Walk — 20 July 2024

Outcome and Highlight

- Future collaborations in organisers of the above events
- Request for more information on Sickle Cell from the general public.
- Patients signed posted to the Croydon Sickle cell and Thalassaemia Centre and Woodenspoon house.
- Patient invited to future events requiring 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 in 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.

In addition, the KCH clinical nurse specialist team have provided the following teaching over the same year period:

- Adult CNS ward teaching sessions on average every fortnight. No written feedback, however, well received with excellent participation by attendees.
- Adult CNS delivered 3 management of sickle cell crisis in pregnancy session to the Kings Denmark Hill midwifery team. Overall rating between 4/5 for each session

- Presentation to Kings pharmacist focusing on sickle cell disease management and pain relief requirement during Black History month
- CNS facilitated monthly (every second Thursday of the month) patient support group information sharing and self-management of condition awareness sessions e.g. accessing welfare, social work and psychology support.
- 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. We have been invited to deliver this session again this year.
- CNS and Consultant attended local primary school (Oct 2023 and 13th March 2024) to raise awareness of the needs of young people with sickle cell disease and importance of a well-structured transition service. The children raised several thousand pounds in support of the transition bag. The school head has pledged continuing future support in this regards.
- CNS attended ASCAT October 2023 and presented on the challenges faced by patients with sickle cell disease and ways in which healthcare professionals can provide patient-centred care.

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

ASCAT (Academy for Sickle Cell and Thalassaemia) led by NHP (National Haemoglobinopathy Panel) Chair, Professor Baba Inusa, with a world-class faculty, and in conjunction with European Haematology Association (EHA) and British Society of Haematology (BSH), hosted its annual conference in London on 25th – 28th October 2023. The theme for 2023 was '*Therapeutic Strategies for Sickle Cell Disease and Thalassaemia: T**ime to Consider a Multi-Modal & Personalised Approach***.'

The 2023 event was a truly international affair, with faculty and speakers featuring prominent clinicians, healthcare professionals, scientists and patient representatives from all over the world - a good number of whom were members of the NHP network. The conference hosted 547 attendees from 46 countries ranging from clinicians, nurses, scientists, pharmacists, haemoglobinopathy charities, service coordinators, pharmaceutical companies, patient representatives, services coordinators and more.

Highlight sessions included the Lancet Commission on SCD launch session, stroke screening in SCD as relates to TCD (transcranial doppler) scans, social determinants of health, focus on gene therapy and other emerging studies and therapies, and pain management, addiction and dependence. Feedback suggests the most popular sessions were the *Overview of Sickle Cell and Thalassaemia,* followed by *Pain Management, Addition and Dependence*. The Gala night

was indeed a wonderful pause for thought – with focus on some vital charity work- balanced out with arts & entertainment, great food and socialising.

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

5.5 SpR Training Day

In September 2023 and March 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. Once again, this was on a virtual platform. We continued to provide this on a virtual platform to allow equitable access for trainees across the country. Delegates received pre-recordings and then joined virtually to watch further recorded and live educational sessions and participated in a live Q&A. The event was hosted by consultants from the SELSE HCC and delegates joined from across the UK. Delegate numbers were restricted to ensure that all attendees could participate despite the new platform. 20 delegates attended in September 2023, and 24 attended the March 2024 session. Delegates come from across the UK and Ireland. Unfortunately, we do not have feedback from these sessions as our administrative support staff has been on long term sick leave. Requests to attend this course continue to outstripe capacity demonstrating this is a well received and well regarded training course among haematology trainees nationally.

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 we are now trying to slowly come away from the original STSTN banner. We are currently working on revamping the website. We are pleased to have been able to do this work with the support of a patient from our cohort. We have obtained a domain referring to the SELSE HCC (www.selsehcc.co.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, at @STSTNetwork and during 2020-21, a YouTube channel was introduced to view recorded presentations of our virtual education events. We have a TikTok account with more than 1000 views.

5.8 HCC/STSTN Newsletters

This year, the HCC/STSTN Red Cell Newsletter has increased publication from twice a year to four times a year. Red Cell News is published across the network hospitals including delivery of hard copies, and electronic copies are on our website (www.ststn.co.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

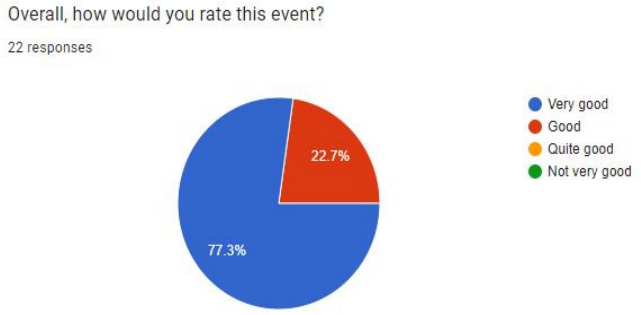
The network's patient forums remain online since the pandemic. They are active throughout the year with the virtual platforms established providing an important continued monthly support network for our patients. Some sites have returned to some in person meetings and there have been moves to encourage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

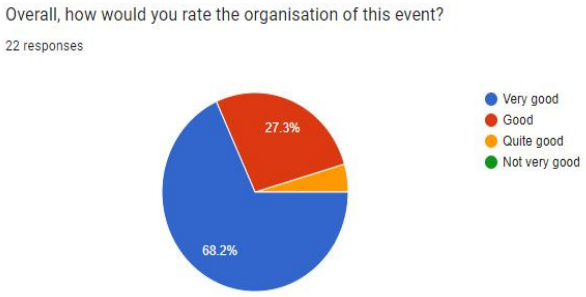
5.10 Patient Awareness Day

An online sickle cell patient awareness day was held in July 2023 with a paediatric morning session and adult afternoon session. This was attended by around 60-70 patients and their relatives.

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 July 2024.

Event Feedback:





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

We ran a teenage workshops at KCH, in January 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.

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 fairly 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 carriers 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 as a whole, many travelling significant distances across England in order to be part of the Peer Review process.

Detailed outcomes and actions arising from of the Peer Review process will be outlined in the annual report 2024-20 25.

6.2 PREM survey

SCD patients frequently experience poor quality of care due to lack of awareness of the condition among non-specialist staff, pre-conceived biases, and unfounded allegation of drug-seeking behaviour. Several reports and surveys using Patient Reported Experience Measure (PREM) tools indicate widespread prevalence of delayed and ineffective provision of pain relief in emergency department, poor access to psychological therapies and poor funding for service development, among others.

To understand patient experience in our network and implement service development based on patient feedback, we used a validated PREM tool to survey patients or carers of sickle cell disease.

The first PREM survey was conducted as part of a network- wide initiative in 2018. We aimed to survey approximately 10% of patients in paediatric and adult sickle services in GSTT, KCH, LGT and CUH. We received 400 responses, which met our collection target.

The survey responses were analysed and problem scores created for specialist care, emergency care, ward-based care, information and support. These problem areas were categorised into domains where further improvement action was needed. We created patient infographics to share these findings with our patients. Individual trusts were tasked to design bespoke QI projects that focussed on their specific problem areas.

A second PREM survey was administered in 2023 to interrogate change in patient experience based on service improvement after our first PREM survey. As before, approximately 10% survey responses were received.

We analysed the responses across five domains: specialist care, emergency care, ward-based care, information, and support. Each response was coded for statistical analysis as a 'problem score,' indicating the presence or absence of an issue, defined as an aspect of healthcare that patients felt could be improved. The survey results, along with agreed service improvement plans, were distributed to patients via infographics. For external benchmarking, we used survey responses from a national pilot study in 2016 (Chakravorty, 2018). Internal benchmarking was conducted through longitudinal comparisons of each SHT over the two survey cycles.

The key problems emerging across the network in the 2018 survey were: SCD knowledge among HCP and timely pain relief in ED, information about SCD treatment options, availability of child-friendly information, chance to meet other people with SCD and SCD related information sharing. Several QI projects were initiated following this survey. Thematic analysis of ED process mapping in one SHT highlighted need for sustained staff education. To improve the effectiveness of pain relief and quality of empathic and informed care in ED, patient co-produced videos were developed and incorporated into mandatory training for staff in two SHTs.

The 2023 survey continued to demonstrate poor experience of care in most problem domains identified in the earlier survey. Patient experience overall was worse compared to the 2018 surveys. Improvement was noted in patients' perception of knowledge among HCP, but this did not translate to better or quicker pain relief in ED. Lack of psychological support was consistent among all respondent groups. Internal benchmarking of SHTs across the two surveys demonstrated improvement in some domains and reflected local QI initiatives. External benchmarking to the 2016 national survey showed fewer problems across all domains in both survey cycles.

The worsening of care experience in the 2023 surveys comes at a time when the NHS has struggled to recover from the pandemic, with longer waiting times in ED, and worsening elective care activity. This has also been a time of the 'cost of living crisis' affecting the poorer areas of the UK, in which our network has a significant representation. We did not survey the same 10% of our cohort, and it is possible that there has been some response bias, with only those with poor experience of care responding to the surveys.

Internal benchmarking has demonstrated that patient led QI initiatives and focused improvement can improve patient experience, although it is likely that external factors may also affect quality of care. Several national SCD improvement projects are currently under way. We will continue to undertake continuous QI methodology (5-D's-define, describe, design, deliver, digest) to ensure sustained improvement in patient- reported areas of service deficit and use PREM tools to inform further service development initiatives.

6.3 Audits

6.3.1 Sickle Cell Disease Acute Pain Episode Audit 2023- Implementing NICE guidance

The aim of this audit is the assessment of the management of sickle cell disease acute pain presentations within the South East London and South East Haemoglobinopathy Coordinating Centre Network compared with published NICE standards in hospital sites.

We increased the data collection period to 4 weeks this year to capture larger cohort. This was particularly relevant for sites with smaller cohorts, who may otherwise not have had any returns. Audit data collection forms were completed for 16 children and 107 adults between 1st February 2023 and 28th February 2023, (123 patients in total). UHL had conducted an identical audit over two months in August and September 2023. A similar audit was also run at QEH. The data from these audits was incorporated, as entirely as possible, into the fields of our HCC wide audit. Active returns were provided by eight hospital sites (Table 1), however some sites with fewer patients experienced no episodes of acute pain presentation during the 28 day audit period.

We also sought to better identify the difference between those attending via London Ambulance Service (LAS) who usually receive their first dose of opiate analgesia in the ambulance, versus those who self-present to ED or those who present to specialist haematology acute pain service/day unit, where this is available.

Table 1

Hospital	Children	Adults
GSTT NHSFT *(Guy's and St Thomas', Evelina Children's Hospital)*	**9**	**97**
King's College Hospital NHSFT *(KCH, Princess Royal University Hospital Orpington)*	**6**	**55**
Croydon University Hospital	**7**	**14**
Queen Elizabeth Hospital	**45**	**NR**
University Hospital Lewisham	**49**	**NR**
Brighton + Sussex University Hospitals *(Princess Royal Sussex, Royal Sussex, Royal Alexandra Children's)*	**NR**	**NR**
Dartford and Gravesham NHST *(Darent Valley Hospital)*	**NR**	**NR**
East Kent NHSFT *(Kent + Canterbury, William Harvey, QEQM Hospitals)*	**NR**	**NR**
East Sussex NHST *(Conquest, Eastbourne)*	**NR**	**NR**
Maidstone + Tunbridge Wells NHSFT *(Maidstone Hospital, Tunbridge Wells Hospital)*	**NR**	**NR**
Medway NHSFT	**NR**	**NR**
Western Sussex Hospitals NHSFT *(St Richard's, Worthing Hospital)*	**NR**	**NR**

Table 1. Data collection forms returned per site

The audit analysed 256 completed data collection forms; 21 children and 235 adults. Age ranged from 1-72 years, mean age 29.17 years, and around 58% of attendees were male (although this field was inconsistently reported).

99% of SCD patients attending HCC hospitals had observations measured and recorded at presentation with pain appropriately assessed (Figure 1). **62% of those presenting in pain received analgesia within 30 minutes of presentation**. The average time to analgesia across the HCC was 51minutes, although in calculating this, we excluded those who had received their first opiate analgesia whilst in London Ambulance Service.

Only 61% received oxygen supplementation if saturations < 95 %, although we are concerned there may have been a systematic error with the reporting of this outcome in the audit, as it was particularly poor (0 and 11%) at two sites in particular. 92% with moderate or severe pain did receive a bolus of strong opiate. 70% were offered paracetamol and 57% were offered a NSAID. No SCD patients presenting with acute pain were offered pethidine. Only 6.8% were seen in a support unit or outpatient setting. Of those accessing support via ED, 45% presented via LAS, and 55% self-presented.

However;

- Initial doses should be given more quickly, acknowledging strain on emergency pathways at the time of audit.
- It is notable that there were junior doctor and LAS strikes occurring during the dates of this audit period, undoubtedly impacting results.

- Procedures to ensure prescription of simple analgesia as an adjunct to opioids should be more robust, although this has improved compared with the audit from the previous year.
- Follow up assessment and monitoring was not performed or documented at optimum frequency.
- Data collection was incomplete in some cases.

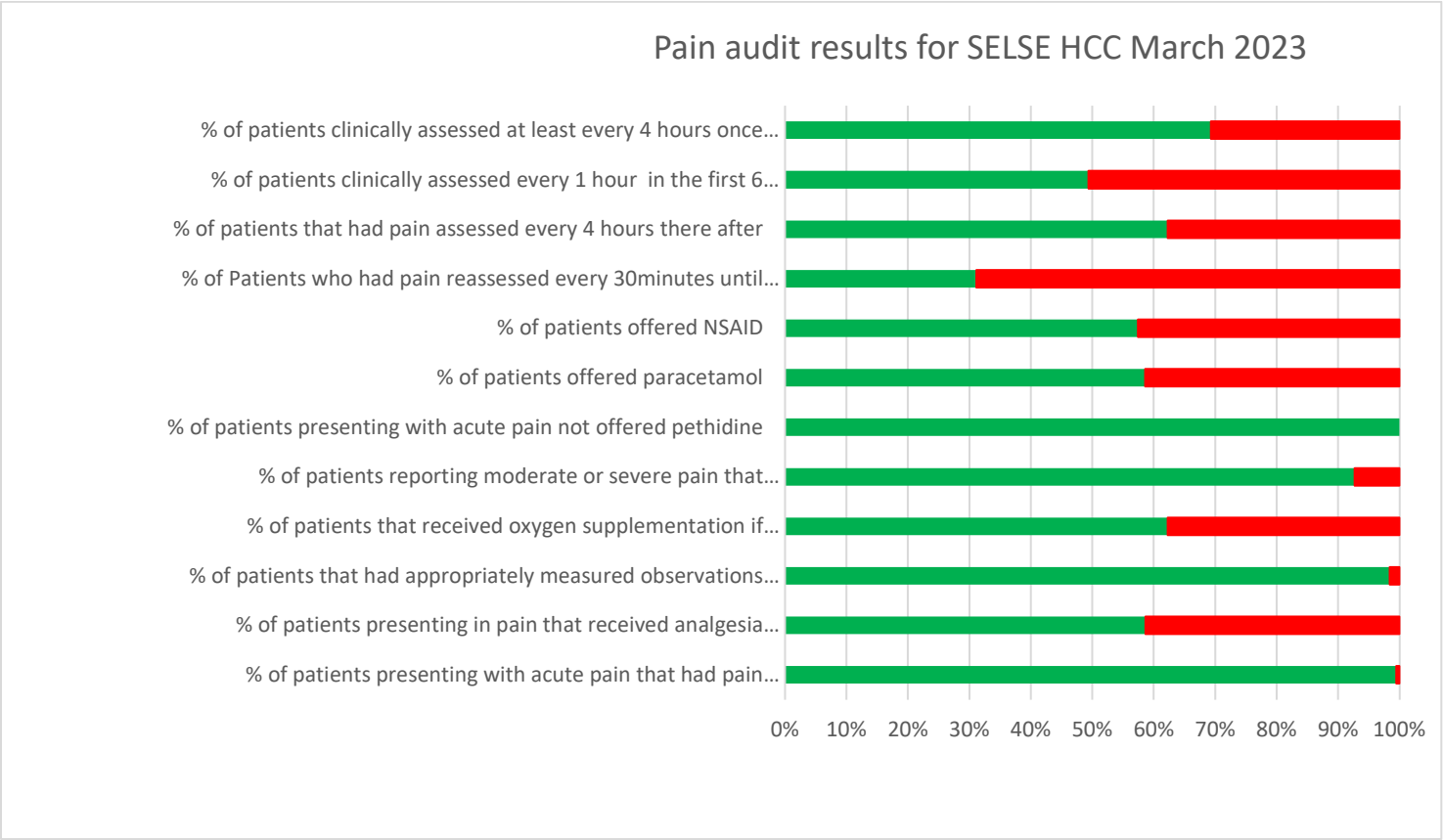


Figure 1. Pain Audit Results for the HCC

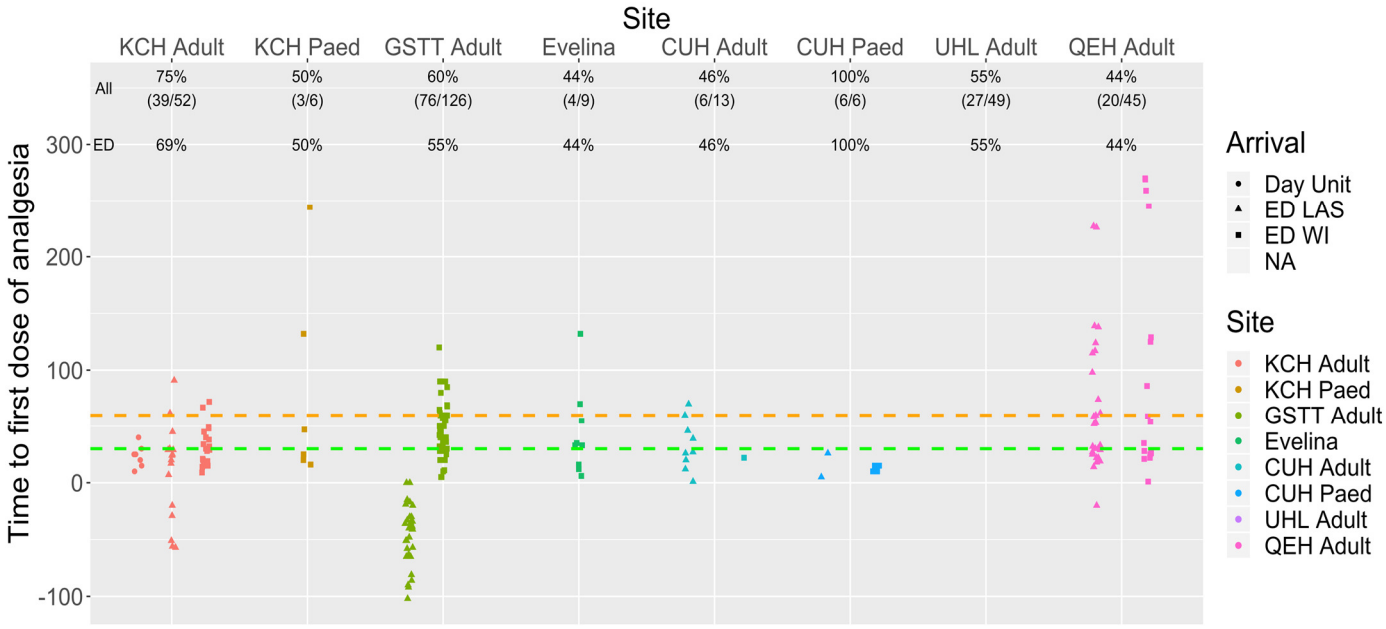


Figure 1 Time to first strong analgesia across SELSE HCC. Where patients received the first dose in the ambulance en route to ED, this is documented as a time less than 0, where 0 is the time they were checked into ED. The green dotted line represents the target of analgesia within 30minutes. The orange dotted line represents 60minutes.

ED- emergency department, WI – arrived as a walk in, LAS – arrived via London Ambulance Service.

7 HCC SELSE Statistics – 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 Chakravoty: 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): Prof Baba Inusa: Baba.Inusa@gstt.nhs.uk
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
Paediatric leads: Dr Adebola Sobande: a.sobande@nhs.net

HCC

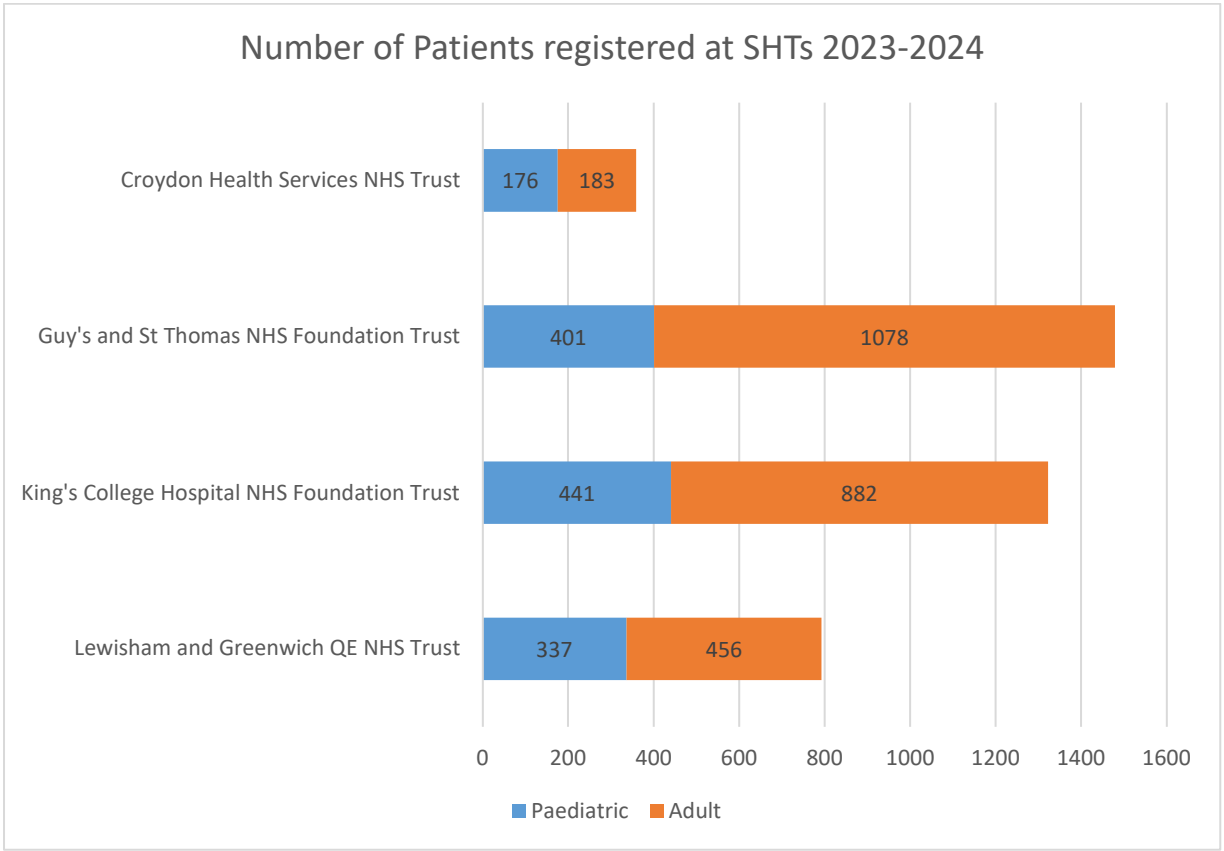
South East London and South East

Dr Sarah Wilkinson: s.wilkinson6@nhs.net

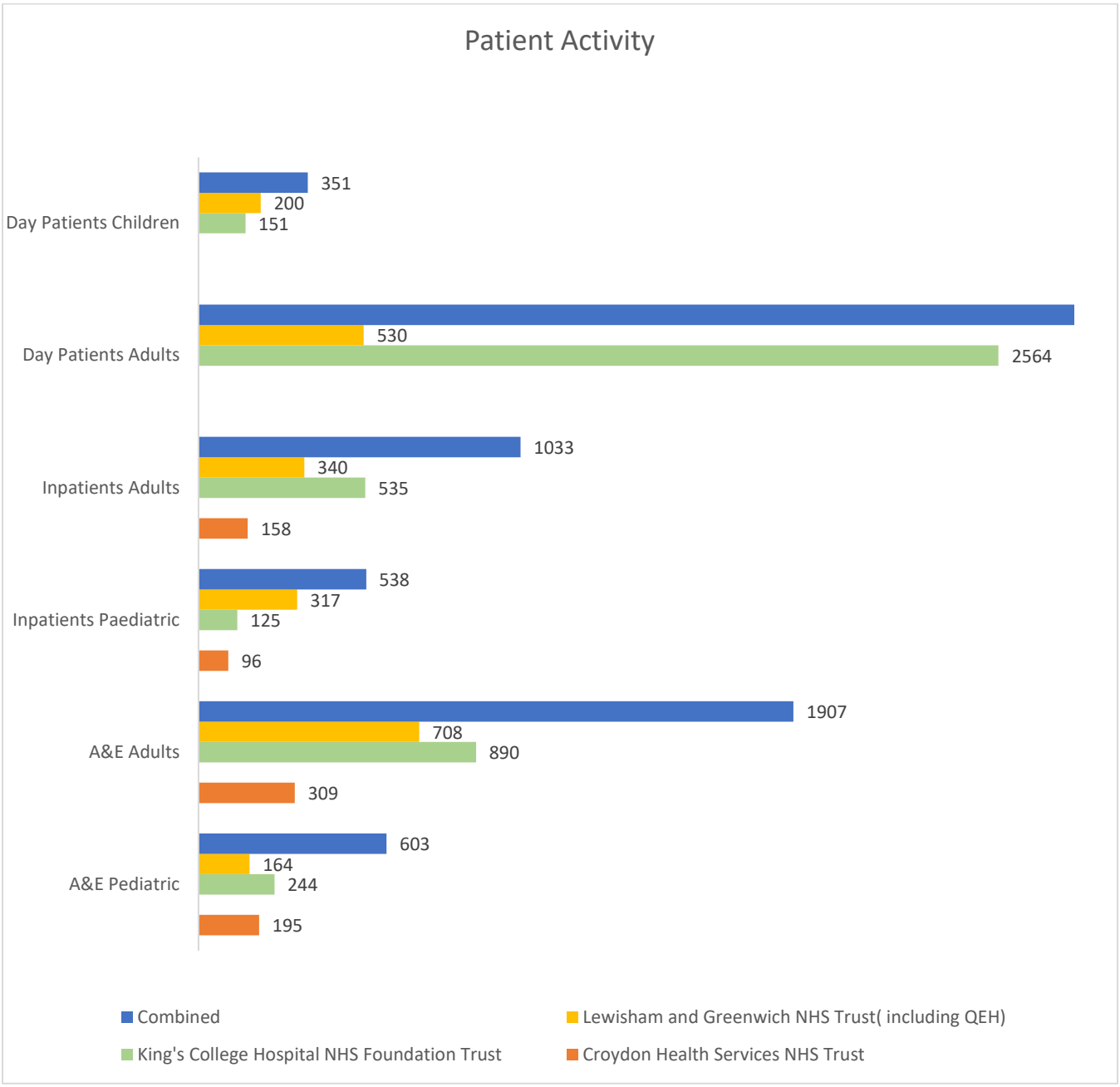
HCC Clinical Leads South East London & South East

Chair:	Dr Sara Stuart- Smith
Deputy chair:	Dr Rachel Kesse-Adu
MDM lead:	Dr Subarna Chakravoty
Deputy MDM lead:	Dr Arne de Kreuk
Audit lead:	Dr John Brewin and Dr Samah Babiker
Guidelines leads:	Dr Rachel Kesse-Adu (adults) and Dr John Brewin (paediatric)
Data leads:	Kate Gardener and Dr John Brewin
Transcranial Doppler leads:	Prof Baba Inusa and Dr John Brewin
Research lead:	Prof David Rees
Education leads:	Dr Rachel Kesse-Adu, Dr Subarna Chakravoty, Dr Moji Awogbade
Outreach lead:	Dr Arne de Kreuk
Annual report lead:	Dr John Brewin
Newborn Screening lead:	Dr Subarna Chakravoty

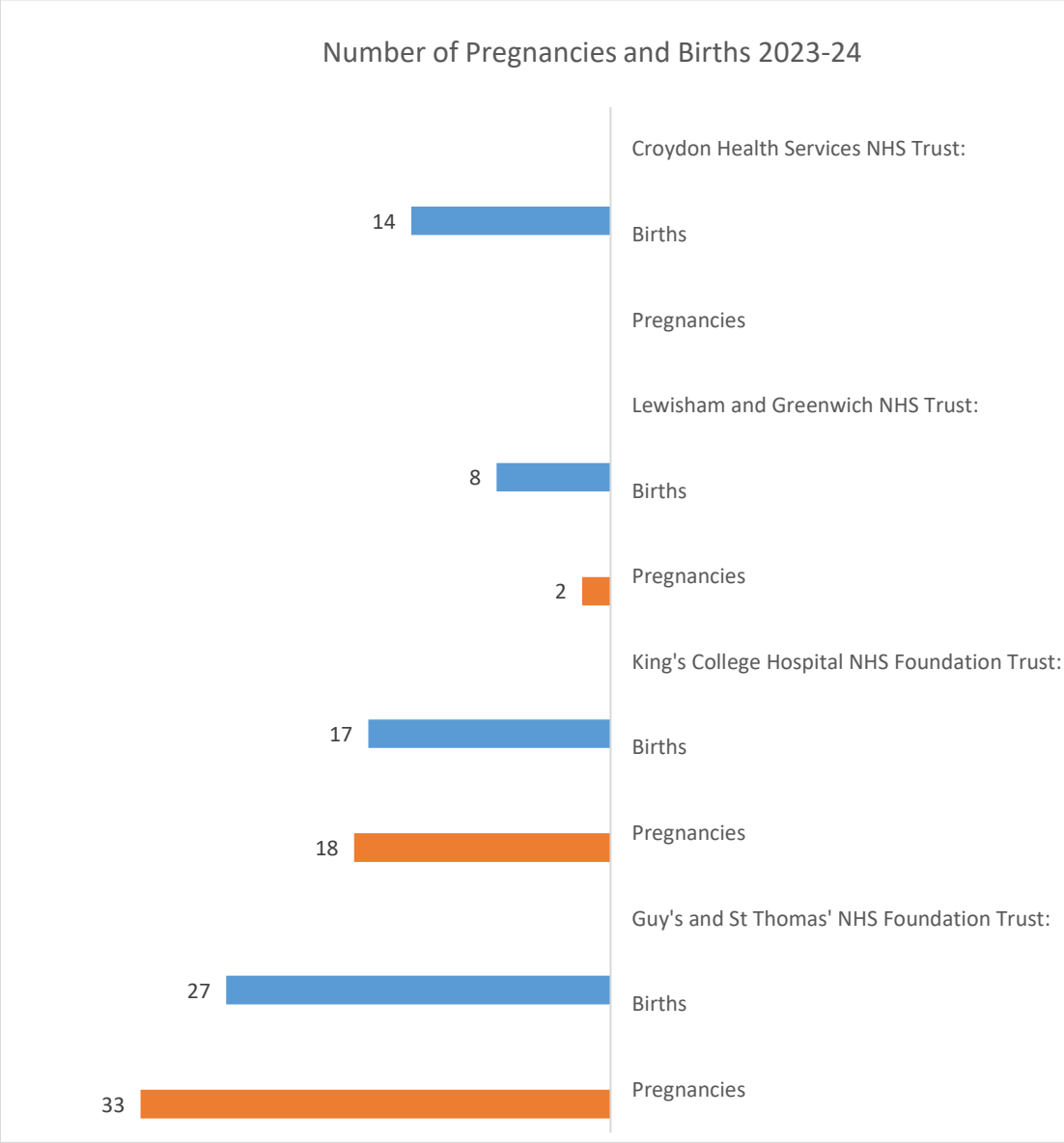
7.1 HCC SELSE – Number of patients across HCC SELSE Network



7.2 HCC SELSE - Patient activity not updated



7.3 HCC SELSE - Number of pregnancies and births



7.4 HCC SELSE - Number of deaths

Number of Deaths	
Croydon Health Services NHS Trust	3
Guy's and St Thomas' NHS Foundation Trust	5
King's College Hospital NHS Foundation Trust	9
Lewisham and Greenwich NHS Trust	5
Total	22

7.5 HCC SELSE - Number of transitions from paediatric to adult services

Number of Transitions	
Croydon Health Services NHS Trust	ND
Guy's and St Thomas' NHS Foundation Trust	18
King's College Hospital NHS Foundation Trust	15
Lewisham and Greenwich NHS Trust	35
Total	68

7.6 HCC SELSE - Number of patients on Hydroxycarbamide

Number of patients on Hydroxycarbamide			
	Paediatric	Adults	Total
Croydon Health Services NHS Trust	73	47	120
Guy's and St Thomas' NHS Foundation Trust	146	250	396
King's College Hospital NHS Foundation Trust	212	238	450
Lewisham and Greenwich NHS Trust	197	98	295
Total	628	633	1222

7.7 HCC SELSE - Number of bone marrow transplants

Number of Bone Marrow Transplants			
	Paediatric	Adults	Total
Croydon Health Services NHS Trust	ND	ND	ND
Guy's and St Thomas' NHS Foundation Trust	ND	3	3
King's College Hospital NHS Foundation Trust	0	8	8
Lewisham and Greenwich NHS Trust	0	0	0
Total	6	11	11

7.8 HCC SELSE – Number of patients started on new therapies (Crizanlizumab/ voxelotor) Patients are no longer on these medications.

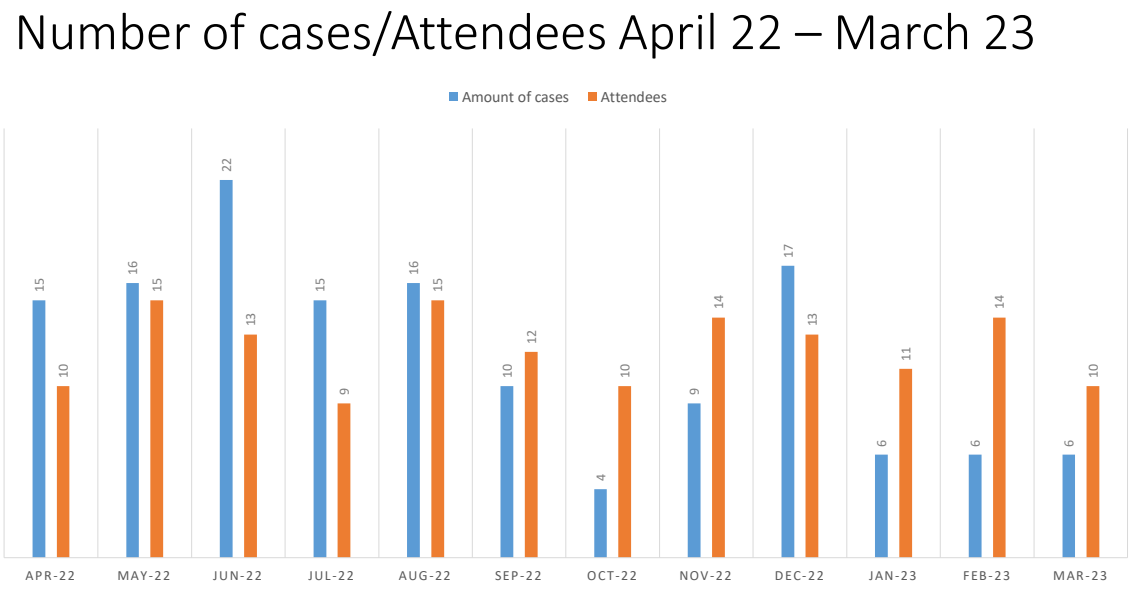
- During the financial year 2023/2024 patient access to all new therapies, including crizanlizumab and voxelotor were withdrawn. We therefore have no patients using these two novel therapies, and continug to look to the future for new agents, including gene therapy to become available.

7.9 SELSE HCC - MDM

SELSE 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.

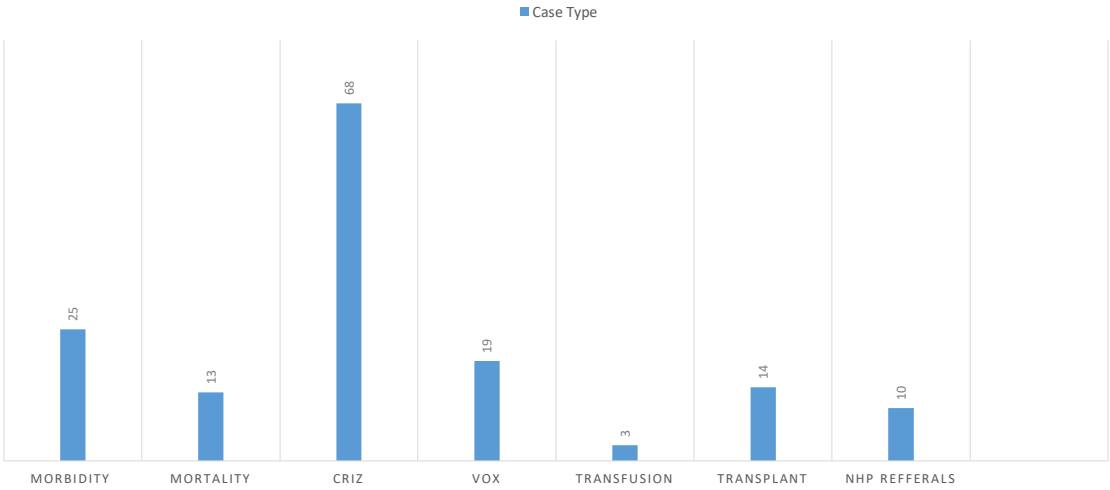
The HCC MDM refers cases as required to the NHP MDM, in line with NHSE policy. We referred 11 cases to the NHP during this period of review. Nine of these were gaining approval for sibling bone marrow transplant according to the eligibility criteria. The other two cases were to review complications of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

Unfortunately detailed data for MDMs held between April 2023 and March 2024 is not available for this annual report because it was stored on a Trust laptop belonging to a member of staff who has been on long-term sick leave and the laptop has been unavailable. We plan to include this data in the 2024-25 annual report.



Total Cases: 142
Average Attendees: 12

Type of cases April 2022 – March 23



7.10 SELSE HCC– M & M

Six cases were subject to in-depth M&M review during the financial year 2023-24. Individualised learning objectives were identified where appropriate and actioned outside the scope of this report. A summary of key findings is given below:

- Three patients died in the community unexpectedly. The PM was inconclusive for 2 cases. The third case, a young woman, died of acute right ventricular failure due to unprovoked pulmonary embolism.
- One patient died unexpectedly from cardiac arrest in hospital following a minor procedure and simple uncomplicated VOC. No clear cause for cardiac arrest – a post mortem echocardiogram was considered but uncertain whether this took place. The case prompted the discussion on risk assessment for ventricular arrhythmias and sudden death in (particular in male) sickle cell patients via echocardiography and 24-hour Holter monitoring. Reference was made to the recent paper by d'Humieres et al., Blood 2023;142(5):409-420. This study suggested a Global Longitudinal Strain (GLS) cutoff of –17.5% for predicting ventricular arrhythmias with a sensitivity of 82% and a specificity of 63%. Further discussion is required whether this parameter should be requested routinely for annual review echocardiography screening.
- One patient developed fat embolism syndrome with severe brain damage as a result. She died after a prolonged state of coma in ITU.
- One patient with multiple end-stage comorbidities died as a result of multi-organ failure against a background of sepsis. She had a period of a delayed haemolytic transfusion a few weeks earlier, but this was not deemed related to the cause of death or sepsis.

The case review identified some shortcomings in care, none related to the causes of death:

- One patient ran out of hydroxycarbamide due to multiple clinic appointment cancellations (strikes)
- One patient (who died in the community) never received a call back from 111 and waited several hours whilst deteriorating. This will be addressed during an inquest hearing.
- Lack of communication between two hospitals (renal at DGH, haematology at SHT) regarding special needs for blood transfusion in SCD. Allo-antibodies and previous DHTR not acknowledged, leading to new episode. Importance of local BT labs always to check SpICE.

- Review and adjustment of analgesia care plans for patients with severe CKD – for example fentanyl instead of oxycodone / morphine.

7.11 HCC SSQD 2023-2024

Indicator	Theme	HCC Indicator 2023-24	Data	Status	Notes
HAEMCC01	Referrals	Number of cases referred to the HCC for specialist discussion	ND	✓	
HAEMCC02	Referrals	Proportion of patients that are referred for clinical advice and guidance to the national panel	ND	✓	
HAEMCC03	Length of Stay	Average length of stay for patients following emergency admission across HCC referring organisations		>	needs clarification
HAEMCC04	Serious Events	Proportion of serious events entered onto NHR by SHTs and reviewed at the HCC morbidity/mortality meetings	22	✓	Only deaths
HAEMCC05	NHR Database	Proportion of patients entered on to the NHR database across the HCC		✓	NHR mapping of patients completed towards end of 2022 leading to much improved correlation of local and NHR databases
HAEMCC08b	LoS	Proportion of patients that have admissions resulting in length of stay over 20 days	51	✓	GSTT, KING'S
HAEMCC09A	SUIs	Proportion of significant complications (as defined by NHR) that are discussed at the HCC morbidity/mortality meetings	100%	✓	
HAEMCC09b	Mortality	Proportion of patient deaths discussed at HCC morbidity/mortality meetings	100%	✓	
HAEMCC12	Treatment	Proportion of patients referred for gene therapy and haematopoetic stem cell transplantation	22	✓	Gene therapy not yet available, but many being put forward for HSCT

7.12 SHT SSQD 2023-2024

Indicator	Theme	SHT Indicator 2023-24: KCH,GSTT,L&G,CRO	Data	Status	Notes
HAEM02	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	82%	✓	
HAEM03i	Pain relief	Percentage of patients given pain relief within half an hour of presentation with sickle crisis, as per NICE guidelines	59%	✓	
HAEM04A	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	100%	✓	
HAEM04Bi	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	95%	✓	
HAEM05	Annual review via NHR	Proportion of annual reviews recorded by NHR	82%	✓	
HAEM06Ai	Adequacy of chelation	Proportion of eligible patients on long term transfusion who receive cardiac MRI	85%	✓	
HAEM07	Utilisation of Hydroxycarbamide	Proportion of eligible children (> 9 months of age) who are offered Hydroxycarbamide	75%	✓	Only patients currently taking, more than 90% are offered

HAEM08	Utilisation of Hydroxycarbamide	Proportion of eligible adults who are offered Hydroxycarbamide	48%	✓	Only patients currently taking, more than 90% are offered
HAEM09a	Assessment of modality of regular transfusion programmes	Proportion of regularly transfused paediatric patients on an automated transfusion programme (simple top-up transfusions)	74%	✓	
HAEM09b	Assessment of modality of regular transfusion programmes	Proportion of regularly transfused adult patients on an automated transfusion programme (simple top-up transfusions)	7%	✓	
HAEM10a	Assessment of modality of regular transfusion programmes	Proportion of regularly transfused paediatric patients on an automated transfusion programme (manual exchange transfusion)	0%	✓	
HAEM10b	Assessment of modality of regular transfusion programmes	Proportion of regularly transfused adult patients on an automated transfusion programme (manual exchange transfusion)	0%	✓	
HAEM11a	Assessment of modality of regular transfusion programmes	Proportion of regularly transfused paediatric patients on an automated transfusion programme (automated exchange transfusion)	26%	✓	
HAEM11b	Assessment of modality of regular transfusion programmes	Proportion of regularly transfused adult patients on an automated transfusion programme (automated exchange transfusion)	93%	✓	

7.13 HCC Self Declaration 2021-2 / 2022-3

HCC – Progress versus Self Declaration Requirements	Status		HCC SELSE
Patient Experience	2022-23	2023-24	**Notes**
The HCC arranges a consistent approach to the formulation of the patient experience exercise which is undertaken at least biennially	✓	✓	
The HCC will monitor a consistent approach to the patient information available in the SHTs	✓	✓	
Structure and Process	✓	✓	
There is a policy and process in place for establishing an MDT to discuss complex cases	✓	✓	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	✓	✓	
The HCC has a training and education strategy	✓	✓	
There is a named lead for trans-cranial doppler screenings	✓	✓	
The HCC attends national haemoglobinopathy panel meetings	✓	✓	
There are agreed clinical guidelines in place as detailed within the service specification	✓	✓	
The HCC will formulate and agree clinical pathways and protocols across the geographical area as detailed within the	✓	✓	
The HCC consider patients for clinical trials and other well designed studies	✓	✓	

7.14 SHT Self Declaration 2021-2 / 2022-3

SHT – Progress versus Self Declaration Requirements	Status		SELSE SHT: - KCH, GSTT, L&G, CRO
Patient Experience	2021-22	2022-23	**Notes**
The SHT participates in PREM activity and undertakes a patient experience exercise at least annually reviewing the results which arise	✓	✓	21-22 CQI project to respond to issues raised in PREM survey 22-23 To repeat PREM survey
There is agreed patient information available	✓	✓	
Structure and Process	✓	✓	
There is a multidisciplinary team in place as per the service specification	✓	✓	
The MDT meet at least monthly and include core members listed in 301 above	✓	✓	Observer and/or wider attendance eg LHT to be encouraged
The SHT has a process in place for TCD scanning	✓	✓	
There must be transition pathways in place as defined within the service specification	✓	✓	
The SHT agree the HCC patient pathways as per the specification	✓	✓	
The SHT agree the HCC clinical guidelines as per the specification	✓	✓	
The SHT submits data to the National Haemoglobinopathy Register	✓	✓	

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	Enrollment: 344 Age: 12-65yrs Sex: All	Study Start: 26/03/2021 Primary Completion: Dec 2025 Study Completion: Dec 2026	KCH paeds 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	Enrollment: 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. 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.

The project has expanded from adults at Guy's Hospital and King's College Hospital to now include Nottingham and Lewisham, and we are setting up in Manchester. 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. This project has funding for a five year period but we anticipate that this will be an ongoing project.

From September 2021, we have recruited over 750 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 re-start in 2024 with the additional support of a Genomics England diverse data drive.

8.3 Publications

(In chronological order)

1: Dimitrievska M, Bansal D, Vitale M, Strouboulis J, Miccio A, Nicolaides KH, El Hoss S, Shangaris P, Jacków-Malinowska J. Revolutionising healing: Gene Editing's breakthrough against sickle cell disease. Blood Rev. 2024 May;65:101185. doi: 10.1016/j.blre.2024.101185. Epub 2024 Mar 7. PMID: 38493007.

2: Canciani G, Palumbo G, Brewin J, Rossi F, Ceglie G. Editorial: Recent advances in pediatric red blood cells disorders. Front Pediatr. 2024 Apr 3;12:1403651. doi: 10.3389/fped.2024.1403651. PMID: 38633330; PMCID: PMC11021739.

3: Al-Samkari H, Shehata N, Lang-Robertson K, Bianchi P, Glenthøj A, Sheth S, Neufeld EJ, Rees DC, Chonat S, Kuo KHM, Rothman JA, Barcellini W, van Beers EJ, Pospíšilová D, Shah AJ, van Wijk R, Glader B, Mañú Pereira MDM, Andres O, Kalfa TA, Eber SW, Gallagher PG, Kwiatkowski JL, Galacteros F, Lander C, Watson A, Elbard R, Peereboom

D, Grace RF. Diagnosis and management of pyruvate kinase deficiency: international expert guidelines. Lancet Haematol. 2024 Mar;11(3):e228-e239. doi: 10.1016/S2352-3026(23)00377-0. Epub 2024 Feb 5. PMID: 38330977.

4: Chakravorty S, Drasar E, Kaya B, Kesse-Adu R, Velangi M, Wright J, Howard J. UK Haemoglobin Disorders Peer Review: A Quality Standards-based review programme for sickle cell disease and thalassaemia. Br J Haematol. 2024 Feb;204(2):668-676. doi: 10.1111/bjh.19114. Epub 2023 Oct 3. PMID: 37786398.

5: Bouyssou I, El Hoss S, Doderer-Lang C, Schoenhals M, Rasoloharimanana LT, Vigan-Womas I, Ratsimbasoa A, Abate A, Golassa L, Mabilotte S, Kessler P, Guillotte-Blisnick M, Martinez FJ, Chitnis CE, Strouboulis J, Ménard D. Unveiling P. vivax invasion pathways in Duffy-negative individuals. Cell Host Microbe. 2023 Dec 13;31(12):2080-2092.e5. doi: 10.1016/j.chom.2023.11.007. Epub 2023 Dec 5. PMID: 38056460; PMCID: PMC10727064.

6: Pellegrini M, Chakravorty S, Del Mar Manu Pereira M, Gulbis B, Gilmour-Hamilton C, Hayes S, de Montalembert M, Inusa BPD, Colombatti R, Roy NB. Sickle cell disease: embedding patient participation into an international conference can transform the role of lived experience. Orphanet J Rare Dis. 2023 Nov 1;18(1):341. doi: 10.1186/s13023-023-02951-8. PMID: 37908000; PMCID: PMC10619309.

7: Stewart GW, Gibson JS, Rees DC. The cation-leaky hereditary stomatocytosis syndromes: A tale of six proteins. Br J Haematol. 2023 Nov;203(4):509-522. doi: 10.1111/bjh.19093. Epub 2023 Sep 7. PMID: 37679660.

8: Di Mauro M, El Hoss S, Nardo-Marino A, Stuart-Smith S, Strouboulis J, Gibson JS, Rees DC, Brewin JN. Males with sickle cell disease have higher risks of cerebrovascular disease, increased inflammation, and a reduced response to hydroxyurea. Am J Hematol. 2023 Nov;98(11):E341-E344. doi: 10.1002/ajh.27074. Epub 2023 Aug 30. PMID: 37646569.

9: Daniels DE, Ferrer-Vicens I, Hawksworth J, Andrienko TN, Finnie EM, Bretherton NS, Ferguson DCJ, Oliveira ASF, Szeto JA, Wilson MC, Brewin JN, Frayne J. Human cellular model systems of β-thalassemia enable in-depth analysis of disease phenotype. Nat Commun. 2023 Oct 6;14(1):6260. doi: 10.1038/s41467-023-41961-9. PMID: 37803026; PMCID: PMC10558456.

10: Asher S, Shah R, Ings S, Horder J, Newrick F, Nesr G, Kesse Adu R, Streetly M, Trompeter S, Lee L, Wisniowski B, Mahmood S, Xu K, Papanikalaou X, McMillan A, Popat R, Yong K, Sive J, Kyriakou C, Rabin N. Haematopoietic stem cell mobilisation followed by high-dose chemotherapy and autologous stem cell transplantation for patients with sickle cell disease and myeloma. Br J Haematol. 2023 Sep;202(6):1224-1227. doi: 10.1111/bjh.18990. Epub 2023 Jul 24. PMID: 37488061.

11: Rankine-Mullings A, Keenan R, Chakravorty S, Inusa B, Telfer P, Velangi M, Ware RE, Moss JJ, Lloyd AL, Edwards S, Mulla H. Efficacy, safety, and pharmacokinetics of a new, ready-to-use, liquid hydroxyurea in children with sickle cell anemia. Blood Adv. 2023 Aug 22;7(16):4319-4322. doi: 10.1182/bloodadvances.2023010099. PMID: 37171600; PMCID: PMC10424132.

12: Piel FB, Rees DC, DeBaun MR, Nnodu O, Ranque B, Thompson AA, Ware RE, Abboud MR, Abraham A, Ambrose EE, Andemariam B, Colah R, Colombatti R, Conran N, Costa FF, Cronin RM, de Montalembert M, Elion J, Esrick E, Greenway AL, Idris IM, Issom DZ, Jain D, Jordan LC, Kaplan ZS, King AA, Lloyd-Puryear M, Oppong SA, Sharma A, Sung L, Tshilolo L, Wilkie DJ, Ohene-Frempong K. Defining global strategies to improve outcomes in sickle cell disease: a Lancet Haematology Commission. Lancet Haematol. 2023 Aug;10(8):e633-e686. doi: 10.1016/S2352-3026(23)00096-0. Epub 2023 Jul 11. PMID: 37451304; PMCID: PMC11459696.

13: Inusa BPD, Mnika K, Babiker S. An expert review of voxelotor for the treatment of hemolytic anemia in patients with sickle cell disease: 'bridging the gap between laboratory data and patient related outcomes'. Expert Rev Hematol. 2023 Jul-Dec;16(8):585-591. doi: 10.1080/17474086.2023.2226858. Epub 2023 Jun 22. PMID: 37329253.

14: Clayden JD, Stotesbury H, Kawadler JM, Slee A, Kölbel M, Saunders DE, Hood AM, Wilkey O, Layton M, Inusa B, Pelidis M, Chakravorty S, Rees DC, Howard J, Awogbade M, Liossi C, Kirkham FJ, Clark CA. Structural connectivity mediates the relationship between blood oxygenation and cognitive function in sickle cell anemia. Blood Adv. 2023 Jun 13;7(11):2297-2308. doi: 10.1182/bloodadvances.2021006751. PMID: 35947137; PMCID: PMC10225890.

15: Bain BJ, Daniel Y, Henthorn J, de la Salle B, Hogan A, Roy NBA, Mooney C, Langabeer L, Rees DC; BSH Committee. Significant haemoglobinopathies: A guideline for screening and diagnosis: A British Society for Haematology Guideline: A British Society for Haematology Guideline. Br J Haematol. 2023 Jun;201(6):1047-1065. doi: 10.1111/bjh.18794. Epub 2023 Apr 19. PMID: 37271570.

16: Urio F, Nkya S, Mgaya J, Rooks H, Ponsian P, El Hoss S, Mselle T, Makani J, Menzel S. Gender effect on production and enrichment of F cell numbers in sickle cell disease patients in Tanzania. Am J Hematol. 2023 Jun;98(6):E139-E141. doi: 10.1002/ajh.26914. Epub 2023 Mar 28. PMID: 36929589.

17: Strouboulis J, El Hoss S. The effects of chronic glucorticoid stimulation on erythropoiesis in Cushing syndrome. Haematologica. 2023 Apr 1;108(4):947-948.doi: 10.3324/haematol.2022.281355. PMID: 35861018; PMCID: PMC10071124.

18: Sharpe CC, Suddle A, Stuart-Smith S. An Overview of Solid Organ Transplantation in Patients With Sickle Cell Disease. Transplantation. 2023 Mar 1;107(3):596-604. doi: 10.1097/TP.0000000000004305. Epub 2022 Oct 10. PMID: 36210501.

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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

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 April 2023 and March 2024.

Between July and November 2023, the service was fully staffed with the Lead Psychologist (B8a) and newly created Psychologist (B7) both in post. Since November 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 January 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 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

9.1.3 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:

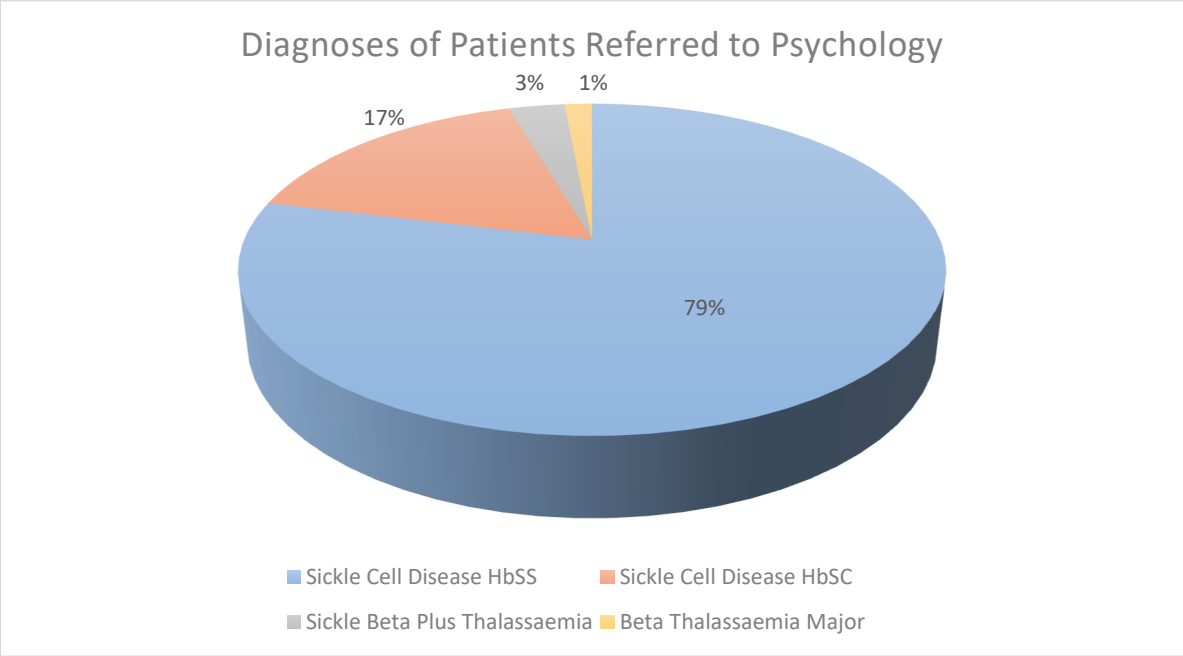
day	session	service	location

Monday	AM	Virtual clinic	WFH
	PM	Virtual clinic	WFH
Tuesday	AM	Hybrid clinic	IT chemotherapy room, DMU
	PM	Virtual clinic	Pod, Caldecott Centre
Wednesday	AM	Hybrid clinic	IT chemotherapy room, DMU
	PM	Hybrid clinic	IT chemotherapy room, DMU
Thursday	AM	Clinical/ non-clinical admin	Office
	PM	Hybrid clinic	Haematology Outpatients
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.

9.1.4 Service provision

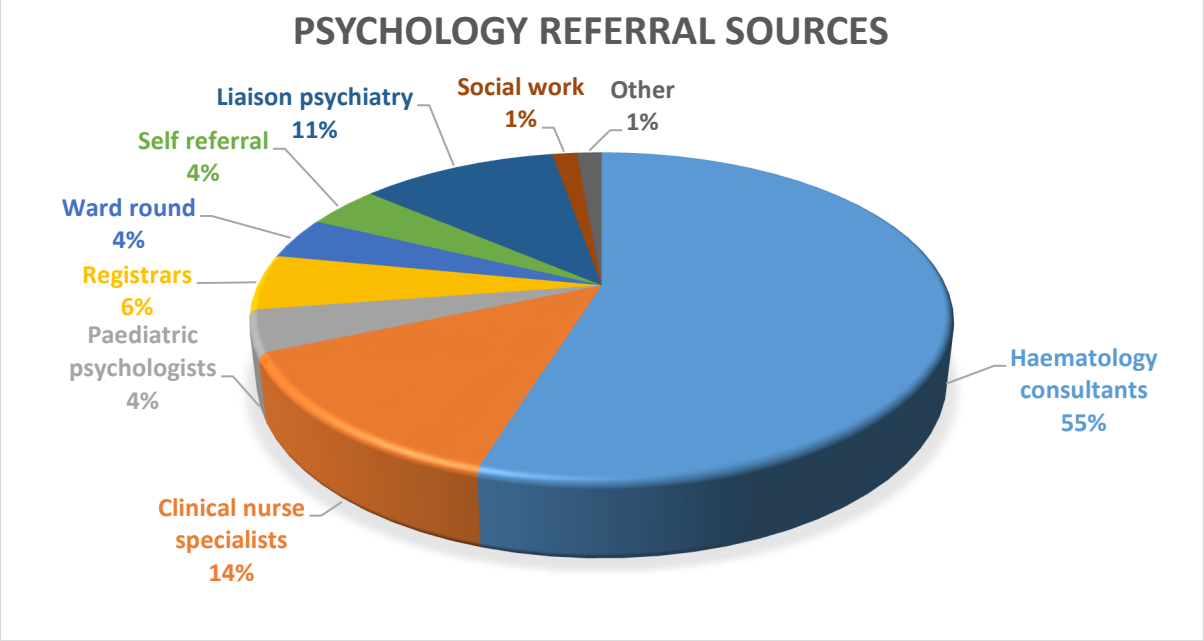
The psychology service provides both inpatient and outpatient support to people with haemoglobinopathies living in South London and Southeast England. The service accepts referrals from patients suffering from any haemoglobinopathy condition. However, the vast majority of patients seen have sickle cell 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 haemoglobinoapathy - 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.

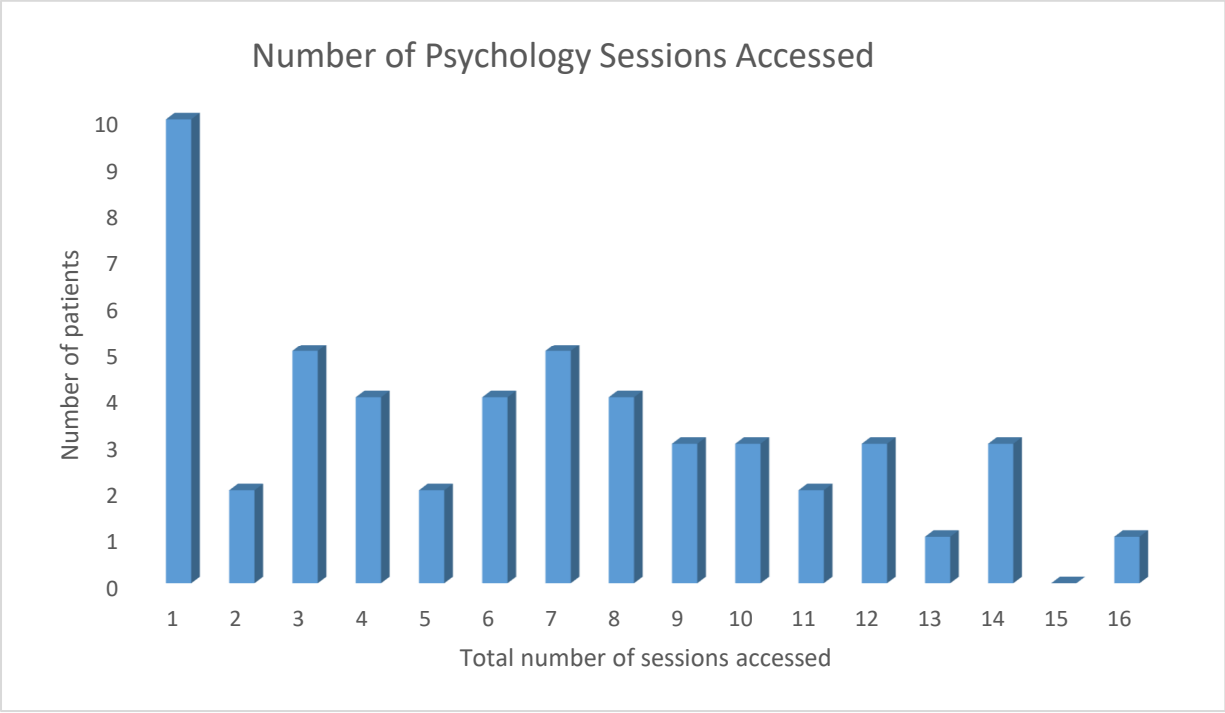


With the introduction of the EPIC electronic health records system, the service has implemented an electronic referral process that has been live since 2024 with the majority of referrals generated by members of the haemoglobinopathies team. However, some referrals are still generated through outpatient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



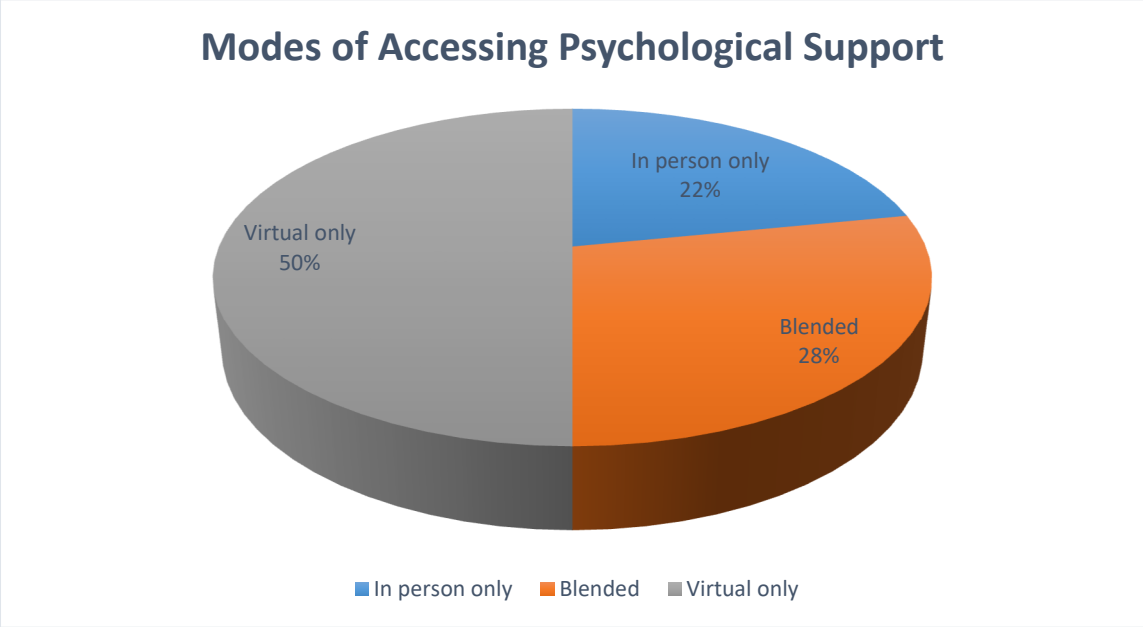
Decisions on which patients to prioritise are made through assessing them and through collaboration with the rest of the haemoglobinopathies team. The service offers a stepped-care approach in order to make a clinical decision on what type of treatment or signposting option is the most appropriate.

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.



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

9.1.5 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.

9.1.6 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 established 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

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 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.

9.2.3 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, mas 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)

9.2.4 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 tome 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 form 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.

9.2.5 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.

9.2.6 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.

9.2.7 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

9.2.8 Service Initiatives and Future Developments

- Use of Q-Interactive to administer neuropsychological assessments digitally and leading to freeing time form 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 found as an attachment)

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 Service Overview

Since 1997, the Haematology HPS has aimed to be a visible, accessible, high-quality service that takes a patient-centred, evidence-based, and needs-led approach to providing psychological support to adults (over the age of 16 years) with blood disorders and their families.

The service expanded most recently in 2019 following a successful business case.

The HPS is mainly located within the haematology department at Guy's Hospital and is therefore well integrated within the multidisciplinary haematology teams*. It also provides some integrated care to the Centre for Haemostasis and Thrombosis at St Thomas' Hospital. We see inpatients and outpatients and offer individual evidence-based psychological therapy, group therapy/support, cognitive assessment, and joint multidisciplinary consultations. See appendix A for pathways. We also work with staff (e.g. medical doctors and ward nurses) to support them in providing quality care. Other key activities include teaching, training, research, audit, offering specialist supervision to other psychologists working in haematology and contributing to the development of psychology in haematology on a London-wide and national basis. We meet regularly with other psychologists across GSTT and are involved in Trust-wide initiatives.

*The advantage of this model is that it increases the visibility and presence of psychology within the healthcare environment and encourages psychological thinking within health care teams. It improves communication between team members and facilitates joint working, both clinically and in research. When psychological services are seen as part of the healthcare team and part of the holistic care the team offers, it makes psychological services more accessible and acceptable to patients and their families, and staff. This can be particularly important when people may be ambivalent about the need for, or social acceptability of, receiving psychological help. Such visibility and accessibility of the service is likely to have contributed to the gradual increase over time in demand for the HPS by both patients and staff.

9.3.3 Service Structure

As of 31/03/24 the HPS comprised of:
0.6wte Consultant Clinical/Health Psychologist and Service Lead (Dr Heather Rawle – since 2002)
0.88wte Band 8b Practitioner Psychologist – vacant since 03/2023 due to post holder being on secondment and deciding not to return; new post holder due to start 04/24
1.0wte Band 8a Highly Specialist Psychologist – Dr Sara Al-Alaway since 10/2023
2.0 wte Band 7 Clinical & Health Psychologists Dr Aisling Daly; since 11/2022; Dr Kiran Bains since 08/2021; Clarissa Odoi since 12/2023
1.0 wte Band 5 Senior Assistant Psychologist - Natalie McLaughlin since 09/2023
0.4 wte Associate Medical Secretary - Tracy Rakshie- since 2020.

There is also a rolling placement programme for trainees and students – current students are Annalise Downs – Cardiff University Psychology Degree 1 year placement; Zoe Guardiola-Abbots – MSc Health Psychology 3 month+ placement.

4.48 wte qualified psychologists + 1.0 Assistant Psychologist cover all adult non-malignant haematology plus myeloproliferative neoplasms and including dedicated support to haemoglobinopathies. About 70% of referrals are related to SCD and thalassaemia so this is equivalent to approximately 3.1 wte of qualified psychology service for SCD and thalassaemia. As GSTT sees approximately 1119 haemoglobinopathy patients, the ratio of qualified psychologists to patients is 1:357 which is under that recommended by national guidelines for Haemoglobinopathy services (1:300)

9.3.4 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 continue 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 thalassemia 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

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 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 September 2022 and Sarah Brennan went on maternity leave June 2023

9.4.3 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 hand 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 had 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.

9.4.4 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 intent 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.

9.4.5 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 coffee morning for parents. Each moth covers a topic, the first being held in June 2024 covering pain management.

9.4.6 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.

9.4.7 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.

9.4.8 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.

9.4.9 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.

9.4.10 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 closes 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

A full report is available in the attachment.
This report details the activity of the Haematology Social work Service at King's College Hospital from 1st May 2023 to 30th April 2024. 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 226 referrals were received for social work support during the period covered by the report; further data will be presented on disease group/ referral source. The predominant reasons for referrals are for financial (20.4% of patients) and housing support (33.9% of patients); however support is provided for a number of issues, including arranging care support (14.9%) and complex discharge planning (5.2%). 35% 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 2023- April 2024 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 Staffing

In March 22 due to staffing changes there was an update of HCC roles and responsibilities. Current staffing is outlined below.

HCC Chair: Dr Sara Stuart-Smith

HCC Deputy Chair: Dr Rachel Kesse-Adu

MDM Chair: Dr Subarna Chakravorty

MDM Deputy Chair: Dr Arne de Kreuk

Audit leads: Dr Samah Babiker/Dr John Brewin

Data leads: Dr Kate Gardner/Dr John Brewin

COVID-19 lead: Dr Kate Gardner

TCD leads: Prof Baba Inusa/Dr John Brewin/ Dr Soundrie Padayachee

Education: Dr Rachel Kesse-Adu/Dr Moji Awogbade

Outreach Lead: Dr Arne de Kreuk

Research Lead: Prof David Rees

PREMS: Dr Subarna Chakravorty

Guidelines: Dr Rachel Kesse-Adu/Dr Sue Height

Annual Report: Dr John Brewin

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 key objectives for 2023/2024 are to:

1. Improve urgent and Emergency Department care and pathways, including piloting a 24/7 ED bypass pathway
2. Enhance community provision including community specialist psychology, benefits and housing support - a successful bid to improve our community offering attracted additional funding of £2 million over 2 years from NHS E
3. Further increase availability and equitable access to red cell exchange and facilitate urgent and out of hours procedures
4. Increase patient engagement and involvement across the network
5. Improve engagement with and support of Local Haemoglobinopathy Treatment centres
6. Update guidelines and referral pathways to reflect service changes and prepare for and complete Peer Review process as an HCC

13 Attachments

13.1 Full Psychology Report (GSTT) (if appropriate)

SCD HCC GSTT Haematology Health

13.2 Social Worker full report

Haem Social Work Annual Report 2023