HCC SOUTH EAST LONDON & SOUTH EAST ANNUAL REPORT

2022-2023

HCC

South East London and South East

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HCC

South East London and South East

1 Introduction

This annual report covers the period April 1st 2022 to March 31st 2023. The South East London and South East Haemoglobinopathy Coordinating Centre (SELSE HCC) continued to provide high quality specialist care for patients with haemoglobinopathies including novel ways of working such as telephone clinics and home delivery of specialist medications.

Highlights of the year include establishing a reduced intensity haematopoietic stem cell transplant (HSCT) programme for adults with sickle cell disease (SCD) having started the programme with the first patient conditioning in November 2021. Crizanlizumab was licensed in the UK in 2021 and received NICE approval in November 2021, as the first new drug in SCD for 30 years. Services to administer Crizanlizumab were developed across the network, including a multidisciplinary approval process, patient information and drug administration. Access to Voxelotor, another new SCD treatment, became available via the Early Access to Medicines Scheme (EAMS) and eligible patients in our network had access to this medication.

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 include a summary of our network response to this report. We welcomed the report, which was a catalyst for closer liaison with non-haematology colleagues, particularly Emergency Department and surgical and pre-admission teams, as well as initiatives including a co-produced patient video with Equality Diversity and Inclusion (EDI) department input and an e-learning educational tool for staff.

We organised an expanded network patient and carer education day with representation from the Sickle Cell Society to discuss changes at each Specialist Haemoglobinopathy Team (SHT) in response to the report. Larger teams launched live 'Current Inpatients Sickle Cell Cohort' census reports, and enhanced education and improved emergency department signage to prioritise those with SCD. The HCC work plan for 2022-23 includes further changes to our services including launching a Cross-Trust Sickle Board for GSTT and KCH tasked with reviewing, monitoring and progressing the proposed work plans, reviewing adverse incidents and sickle-related complaints, with committed membership from across each Trust including emergency medicine, paediatrics, obstetrics, medical and surgical specialities and local sickle teams, and chaired by senior Trust management.

The move to virtual working both in clinical practice, for patient education and support groups, and for administrative and staff educational meetings, has continued. Although we re-introduced face to face clinics, virtual working is integrated into ongoing practice throughout the network. Virtual services have been popular with staff and services users, and allow us to engage more fully with service users, and re-engage with some who previously struggled to attend in person.

The National Haemoglobinopathy Registry (NHR) expanded its functionality this year allowing increased data collection.

With the resumption of relatively normal working since the pandemic peak, we launched a number of research studies across the Network, including the Natural History and Outcomes of SCD Database Study which recently reached a 250 recruitment milestone, and other trials have started or resumed active recruitment.

As outlined in out last Annual Report, the main aims for 2022-2023 were:

- Response to the APPG report including formation of Trust Sickle Boards at larger SHTs
- Inclusion of all SELSE HCC patients on the NHR to allow data collection in real time and monthly data review
- Continued emphasis on education provision including development of a mandated e-learning module for ED
- Consolidation of work with LHTs to include review of referral pathways via new Outreach Lead

- Rolling programme of review of guidelines and pathways
- Patient engagement: patient awareness day (July 22), patient newsletter and patient survey (PREMs), patient representative in SELSE HCC delivery meetings
- Equitable and improved access to the novel therapies including HSCT
- Equitable and improved access to apheresis (red cell exchange transfusion) including an out-of-hours service
- Website update
- Workforce gap analysis

It is satisfying to note that we have made significant progress with these aims, and in particular, we have progressed these three areas across the network:

Clinical progress

- Set up crizanlizumab service at SHTs, overseen by HCC MDT
- Availability of voxelotor via a Named Patient Programme and subsequently via EAMS
- Establishment of adult HSCT programme
- Mapping of LHTs and mapping of patients within NHR
- Transcranial Doppler (TCD) quality assurance (QA) programme established
- Audits of pregnancy outcomes and pain

Improved network educational provision

- HCC Network Nurse Educator established an in person and virtual educational programme
- Ongoing work on lectures for virtual educational hub including Equality, Diversity, and Inclusion (EDI film) and Sickle Acute Pain e-learning module
- Quarterly multidisciplinary network educational sessions
- Biannual SpR MRCPath Haemoglobinopathy training programme

Research output

- Extensive research portfolio including pharma and investigator-led studies
- Set up and commencement of recruitment into the Natural History and Outcomes of SCD Database Study
- Obtaining grant for the haplo-identical HSCT trial REDRESS study

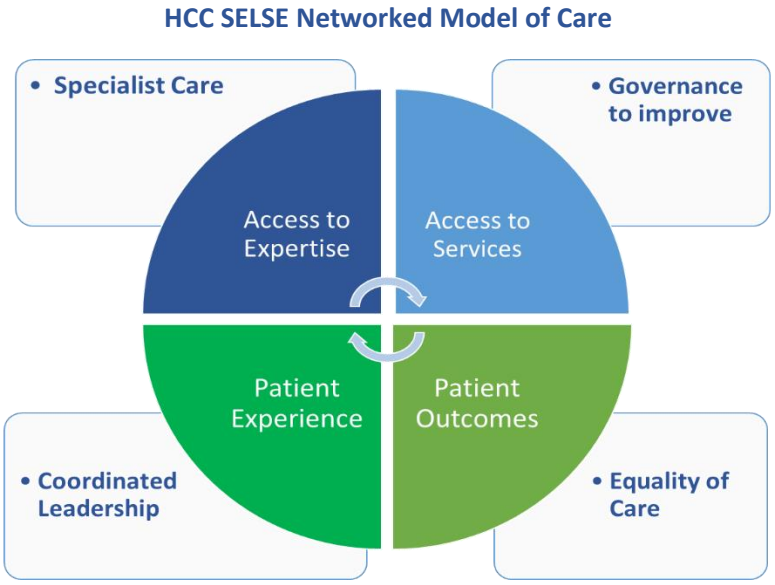
Many thanks to all our staff across the HCC who contributed to this report and worked so hard during 2022/23.

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.

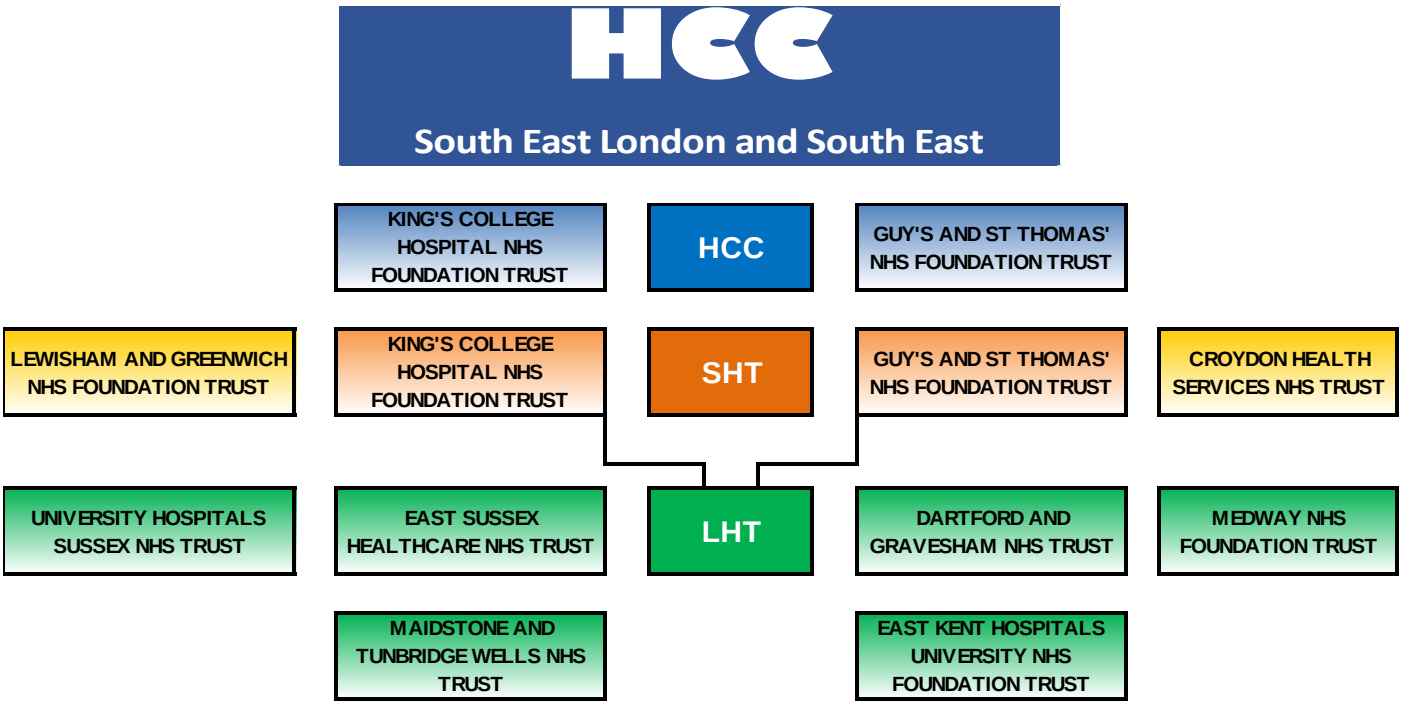


3 HCC Framework

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.

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 2022-23, as we adopted new ways of working to deliver education and training.

5.1 Peer Education Meetings

Our Peer Education Events welcomed participants and speakers from across national and international boundaries, as we harnessed the benefits of virtual education platforms. Our virtual sessions included speaker presentations and Q&A sessions. With speaker's permission, some presentations were uploaded to our YouTube platform.

Peer Education Meetings:

23/02/22 - Pain Management in Sickle Cell and Thalassaemia

20/07/22 - Stem cell transplantation in adult patients with sickle cell disease

08/03/23 - Aneurysms and Stroke in Sickle Cell Event

These sessions were extremely well received. Following the session on aneurysms, we were invited to give the same talks to the Manchester HCC for one of their training days.

5.1.1 October 2022

We hosted a Sickle cell disease preceptorship aimed at consultants and SpRs on 13th and 14th October 2022. There were 18 attendees and the overall feedback rating was 4.8/5.0 and the following feedback summary was received

"The entire event was amazing, great to see the TCD and in the lab. Speakers were all excellent. Small group environment made the session relaxed, enjoyable and easy to ask questions and have discussions."

5.1.2 December 2022

KHP ran an all day virtual session for all Health care professionals who may encounter patients with SCD. It was attended by 31 people. The feedback rating was 4.6/5 with the salient comments in the feedback as follows:

"good to see how different departments come together for patient care, interesting mix of clinical, psychological and social care for SCD patient, good to learn most up-to-date best practice to care for SCD patient, improvements include inclusion of case studies and patients to hear their perspective"

5.1.3 March 2023

KHP ran another live virtual training session for health care professionals. This was attended by 32 people. Feedback was again very positive, with an overall rating of 4.5/5 and the following comments received:

"speakers well-versed and experiences in caring for SCD patients, thorough explanation of SCD pain, informative to hear patient's experience, improvements include wanting to hear more about the link between race and the treatment of sickle patients and a better venue choice"

5.2 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. We have now published 21 issues in total.

5.3 Nurse led Education

The SELSE HCC network offers a variety of training and education modules across the year. Our new Nurse Educator, Sabah Mahmood, helped developed a full programme of face to face and virtual teaching across the network. She had a period of maternity leave across this year period, which we only managed to fill very recently. Therefore, education output is a little down on the previous year, but we anticipate will be back up to usual levels for 2023-24.

In 2022-3, sessions delivered or contributed to included: -

- Kings College Hospital ED bitesize teaching (Paeds and Adults) with four face to face sessions every quarter
- GSTT ED teaching
- GSTT ward teaching
- King's Health Partners educational films – chest crises and pain in ED
- Regular support group presentations and Patient Education forums
- Two network RCN accredited study days. Paediatrics and adults covered in two separate sessions. This is now a rolling programme to deliver three sessions a year across the network with national invitation through PDN forum.
- Part of national education forum across the 10 HCC's delivering teaching sessions.
- Teaching on Haemoglobinopathies module with KCL

5.4 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.

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.

5.5 ASCAT

The Annual Scientific Conference on Sickle Cell and Thalassemia (ASCAT) 2022 conference, in collaboration with European Hematology Association & British Society for Haematology, successfully completed a 3-day conference from 20th – 22nd October 2022. This was the first face to face conference since the COVID -19 pandemic and the lifting of the travel restrictions; an opportunity for networking and sharing of ideas. Almost 400 delegates registered for the event from different NHS Trusts, institutions and a range of different countries. There were attendees from US, UK, various European countries, Asia and Africa.

With the theme of 'Improving the Lives of People Living with Sickle Cell Disease & Thalassaemia' this year's conference heard from groups of patients and patient family members and a Gala Night was introduced to the event. It was a great opportunity for all to interact physically and learn from each other. The event hosted lectures from physicians, nurses, psychiatrists, successful abstracts and patient sessions. The next conference is scheduled for 25th – 28th October 2023.

5.6 SpR Training Day

In September 2022 and March 2023, 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. 22 delegates attended in September 2022, and 19 attended the March 2023 session. Feedback from the two events is shown below.

Sept 2022 - % HOW SATISFIED WERE YOU?	Very Satisfied	Satisfied
With the course overall	64.3%	35.7%
With the organisation of the course?	46.2%	53.7%
With the quality of content and presentations?	57.1%	42.9%
With the course structure?	42.9%	57.1%

Attended: 19

March 2023 - % HOW SATISFIED WERE YOU?	Very Satisfied	Satisfied
With the course overall	78.9%	21.1%
With the organisation of the course?	63.2%	36.8%
With the quality of content and presentations?	63.2%	36.8%
With the course structure?	57.9%	42.1%

5.7 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.

5.8 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.

5.9 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 2023.

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

6 Audit and PREM (Patient Reported Experience Measures)

6.1 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.

Future work: We are currently analysing the second PREM survey. We will create similar infographics for wide dissemination and responses will inform future service development projects.

6.2 Audits

6.2.1 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.

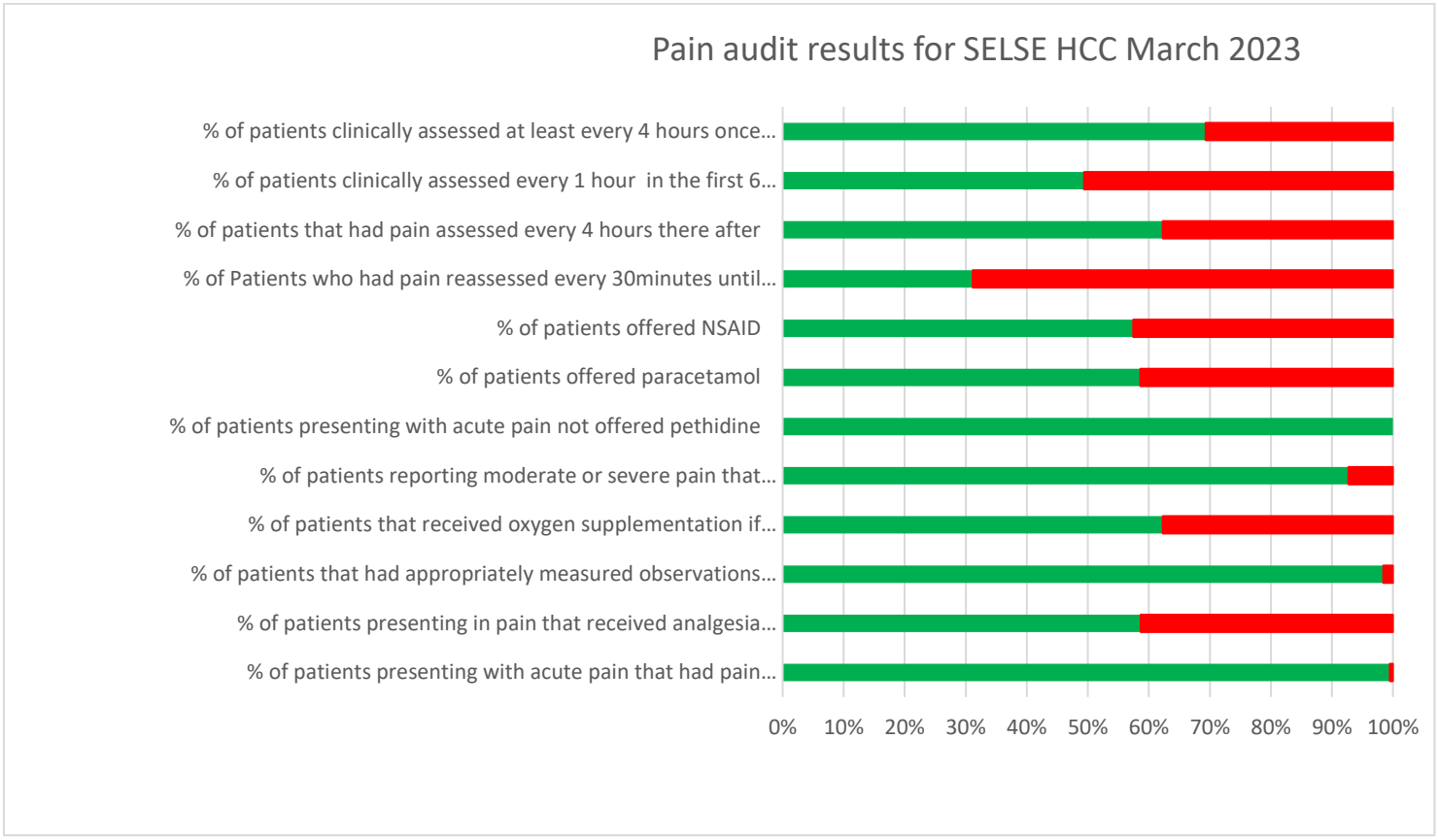


Figure 1. Pain Audit Results for the HCC

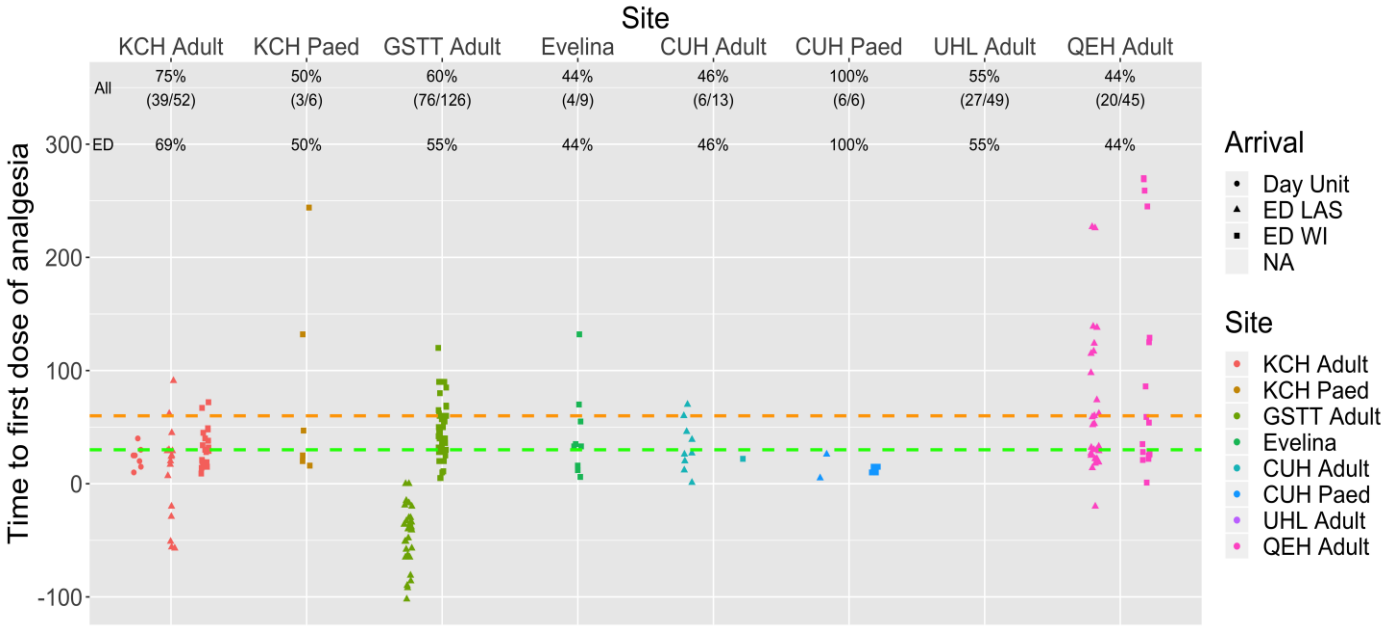


Figure 1 Time to first strong analgesia across SELSE HCC. Where patients received the first dose in the ambulance en route to ED, this is documented as a time less than 0, where 0 is the time they were checked into ED. The green dotted line represents the target of analgesia within 30minutes. The orange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

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

6.2.2 Sickle Cell Disease and Pregnancy Audit 2021

A BSH guideline on the management of pregnancy in SCD was recently published. The aim of this audit was to collect pregnancy outcomes for the last year and audit how well care adhered to the following BSH guideline recommendations:

- Offer preconception counselling and partner testing by 12 weeks
- Offer folic acid pre-conception and throughout pregnancy; penicillin V throughout pregnancy; and aspirin from 12 to 36 weeks gestation
- Hydroxycarbamide and ACEi should be stopped prior to attempting to conceive
- Antenatal care provided by MDT including experienced obstetrician, midwife and haematologist
- Prophylactic LMWH from 28 weeks (beginning of pregnancy if additional risk factors) until six weeks postpartum
- Postpartum contraception advice relayed to primary care

The results were as follows:

Adult standard for pregnancy management in women with sickle cell disorder	KCH	GSTT	UHC	L&G	Maid & TW
Total pregnancies; live births; miscarriages; TOP	23; 18; 3;2	18	4;3	5	1
1. Offered partner screening? And if carrier partner, offered early counselling, 1st trimester Dx and counselling?	100%	100%	100%	100%	100%
2. HU at conception?	2 (Top)	0	0	0	0
3. ACEi at conception?	0	0	0	0	0
4. Antenatal care with MDT incl. experienced obst & midwife a haematologist with links to SHT?	100%	100%	100%	80%	0%
5. Offered folic acid 5mg od pre-conception and throughout pregnancy?	100%	100%	100%	100%	100%
6. Offered aspirin 75-150mg od 12-36/40?	100%	100%	75%	80%	100%
7. Offered penicillin V 250mg bd or alternative throughout pregnancy?	100%	100%	100%	80%	100%
8. Offered Px LMWH from 28 weeks gestation, or from pregnancy presentation if additional risk factors?	100%	100%	100%	80%	100%
9. prescribed Px dose LMWH for 6 weeks post delivery	78%	100%	100%	100%	100%
10. Post-partum contraceptive advice given and conveyed to primary care team?	95%	56%	100%	80%	100%

The two patients who became pregnant while taking hydroxycarbamide both opted for termination of pregnancy as in each case it was an unplanned pregnancy and their decision was made regardless of being on hydroxycarbamide. Overall, we found care was good and already adhered closely to the newly published guidelines. Areas for improvement include documentation of medications given and availability of contraceptive advice where appropriate. We aim to continue this as a yearly audit using the same proforma as that piloted.

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

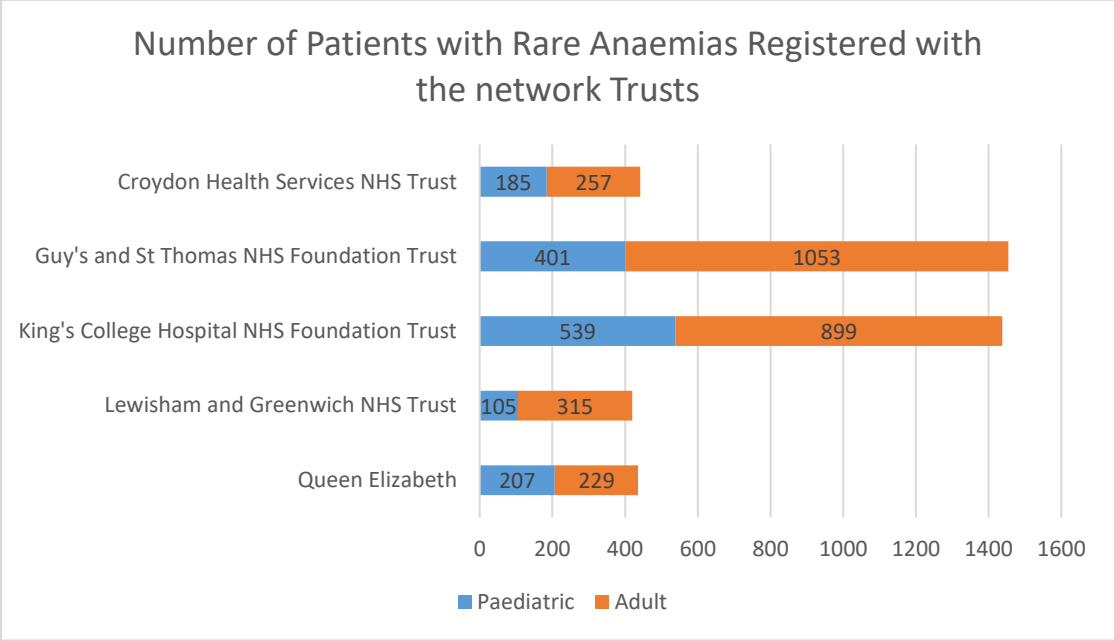
Croydon Health Services NHS Trust (Mayday University Hospital)
Adult lead: Dr Stella Kotsiopoulou: stellakotsiopoulou@nhs.net
Paediatric lead: Dr Nazma Chowdhury; nazmachowdhury@nhs.net

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
Dr Sarah Wilkinson: s.wilkinson6@nhs.net

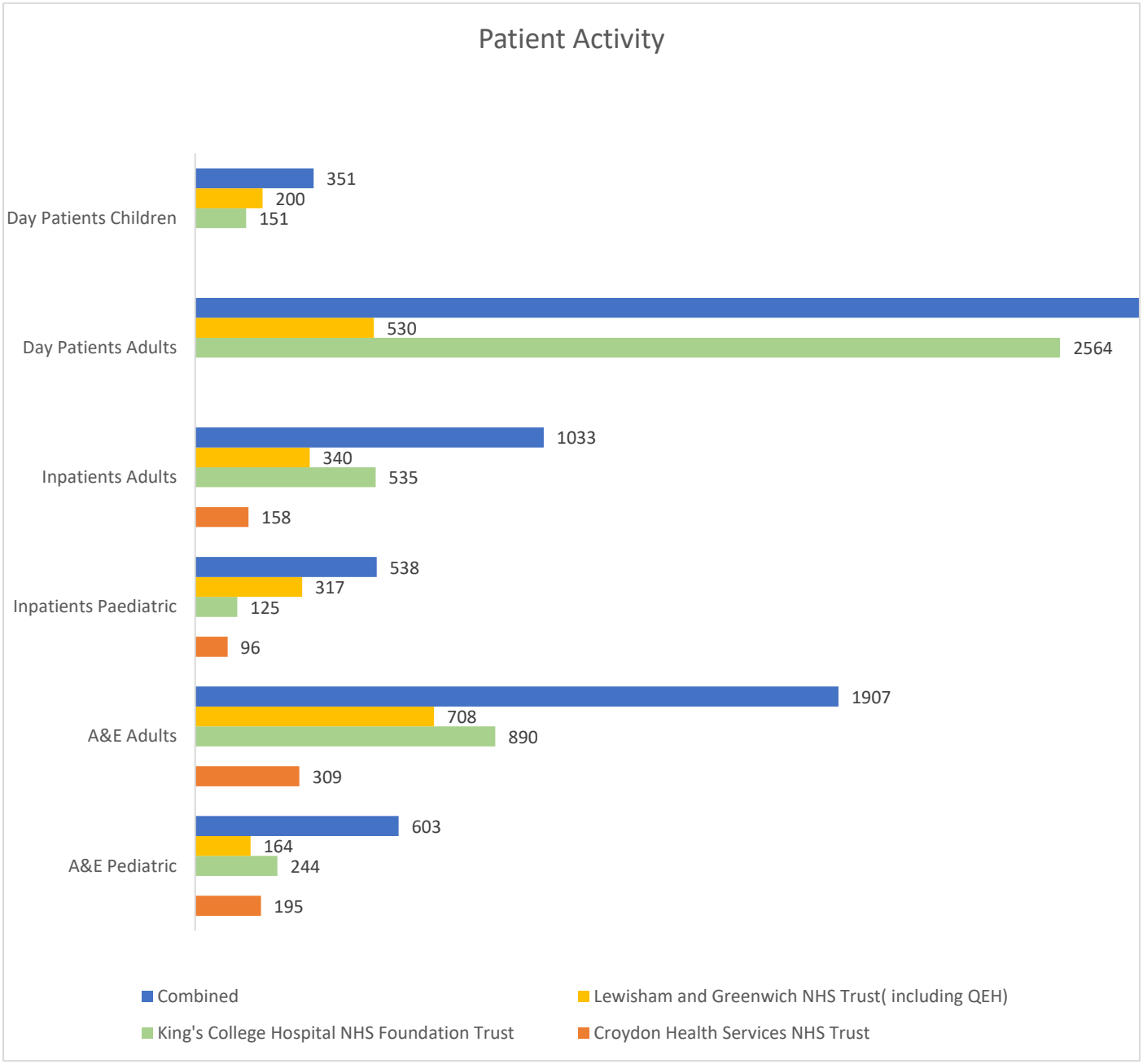
HCC Clinical Leads South East London & South East

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

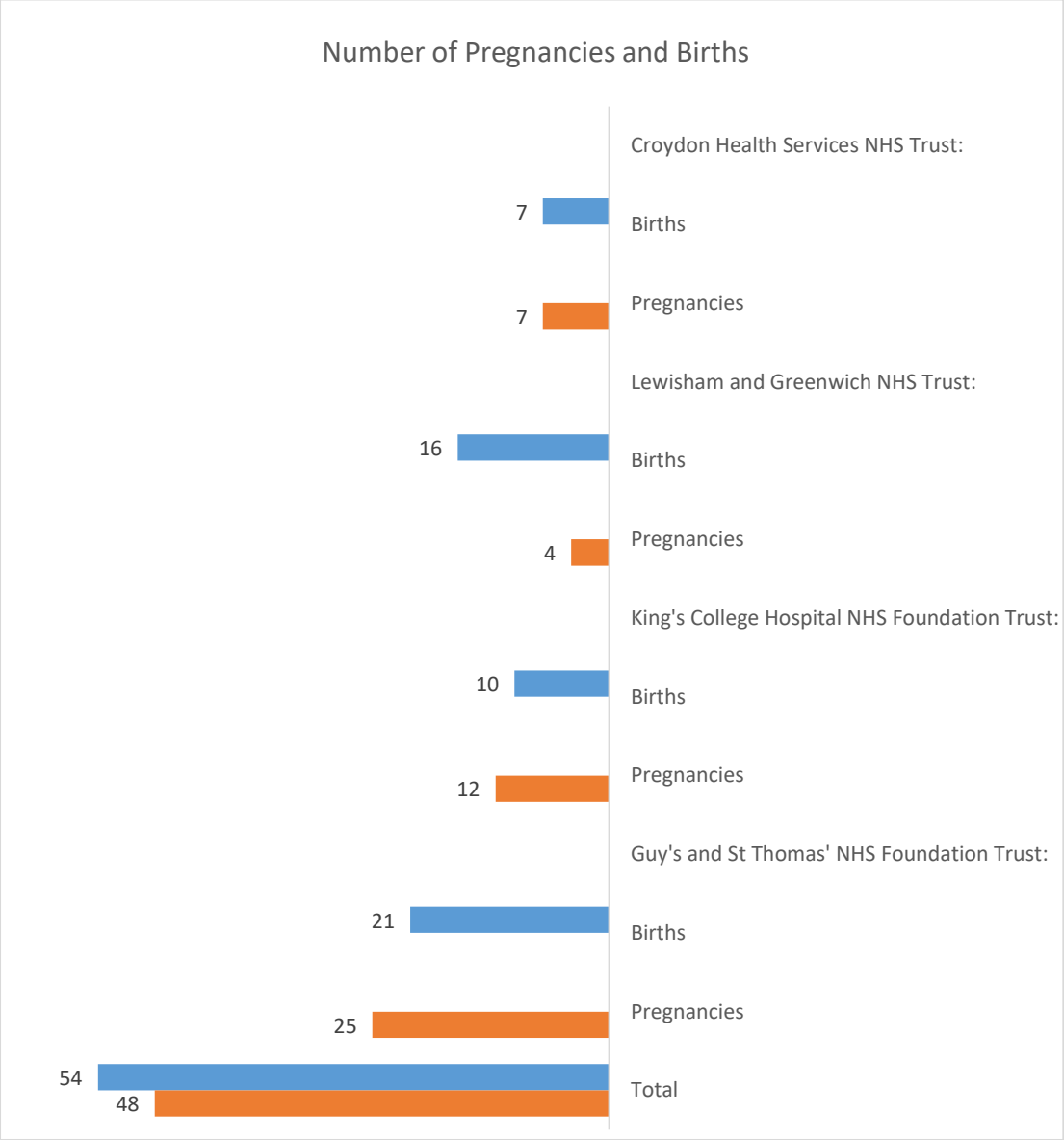
7.1 HCC SELSE – Number of patients across HCC SELSE Network



7.2 HCC SELSE - Patient activity


Patient Activity
Day Patients Children
351
200
151
Day Patients Adults
530
2564
Inpatients Adults
1033
340
535
158
Inpatients Paediatric
538
317
125
96
A&E Adults
1907
708
890
309
A&E Pediatric
603
164
244
195
Combined
Lewisham and Greenwich NHS Trust(including QEH)
King's College Hospital NHS Foundation Trust
Croydon Health Services NHS Trust

7.3 HCC SELSE - Number of pregnancies and births



7.4 HCC SELSE - Number of deaths

Number of Deaths	
Croydon Health Services NHS Trust	0
Guy's and St Thomas' NHS Foundation Trust	12
King's College Hospital NHS Foundation Trust	11
Lewisham and Greenwich NHS Trust	3
Total	26

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

Number of Transitions	
Croydon Health Services NHS Trust	6
Guy's and St Thomas' NHS Foundation Trust	40
King's College Hospital NHS Foundation Trust	21
Lewisham and Greenwich NHS Trust	50
Total	117

7.6 HCC SELSE - Number of patients on Hydroxycarbamide

Number of patients on Hydroxycarbamide			
	Paediatric	Adults	Total
Croydon Health Services NHS Trust	73	41	114
Guy's and St Thomas' NHS Foundation Trust	150	279	429
King's College Hospital NHS Foundation Trust	188	238	426
Lewisham and Greenwich NHS Trust	151	102	253
Total	587	660	1222

7.7 HCC SELSE - Number of bone marrow transplants

Number of Bone Marrow Transplants			
	Paediatric	Adults	Total
Croydon Health Services NHS Trust	1 referred	0	1
Guy's and St Thomas' NHS Foundation Trust	5	4	9
King's College Hospital NHS Foundation Trust	0	5	5
Lewisham and Greenwich NHS Trust	3	0	3
Brighton Royal Sussex	0	1	1
Total	6	10	15

7.8 HCC SELSE – Number of patients started on new therapies (Crizanlizumab/ voxelotor)

The financial year 2021/22 formed a landmark in the field of novel therapies for sickle cell disorder. Crizanlizumab, a p-selectin inhibitor that can lead to a 40-45% reduction of vaso-occlusive events, was approved by NHS England in November 2021. Crizanlizumab was made available under a Managed Access Agreement (MAA) from the 1st of February 2022. On the 17th of February 2022, the first patient in England received a dose of crizanlizumab funded by the NHS at King's College Hospital.

Voxelotor was made available free of charge for NHS patients under a named patient programme initially from August 30th 2022. Following a positive recommendation by MHRA, the named patient programme was replaced by an Early Access to Medicines Scheme (EAMS) in February 2022, again free of charge.

Both new treatment options require approval by the HCC MDT and can be prescribed by HCC or SHTs. Blueteq approval is required and all patients need to sign informed consent to the terms and conditions of the MAA or EMAS scheme, respectively.

The table below summarises the number of patients on novel therapies by March 31st 2023.

Challenges related to the novel therapies include:

- Capacity of day therapy units to accommodate crizanlizumab patients
- Administrative burden due to all cases requiring formal MDT discussion and approval
- Administrative burden EAMS portal for voxelotor

Number of patients started on new therapies as per 31-03-2023	Crizanlizumab	Voxelotor
Croydon Health Services NHS Trust	1	2
Guy's and St Thomas' NHS Foundation Trust	28	NR
King's College Hospital NHS Foundation Trust	18	8
Lewisham and Greenwich NHS Trust	3	3
Total	50	13

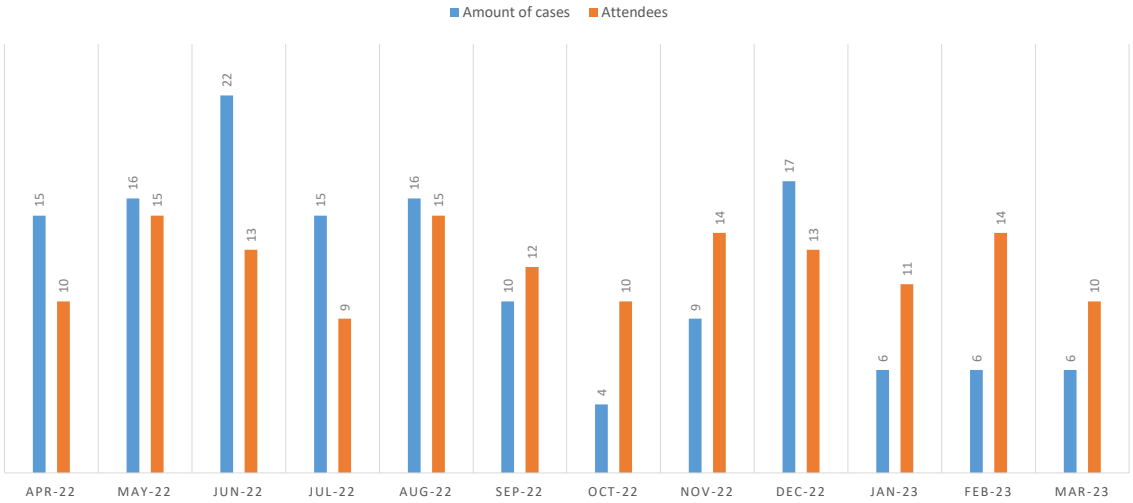
7.9 SELSE HCC– MDM

SELSE HCC continued to hold a virtual monthly Multi-Disciplinary Meetings, chaired by Dr Subarna Chakravorty. Dr Arne de Kreuk was deputy chair. During the reporting year period, Dr Chakrovrty stepped down as chair, Dr De Kreuk took on this role, and Dr Nick Fordham became the deputy chair. The group continued to meet regularly to review complex cases across the region requiring collective senior clinical input.

The workload was increased by the need for discussion of any patient being considered for Crizanlizumab, although this number has decreased again since the less promising clinical trial data become available in December 2022 and dampened uptake on its use.

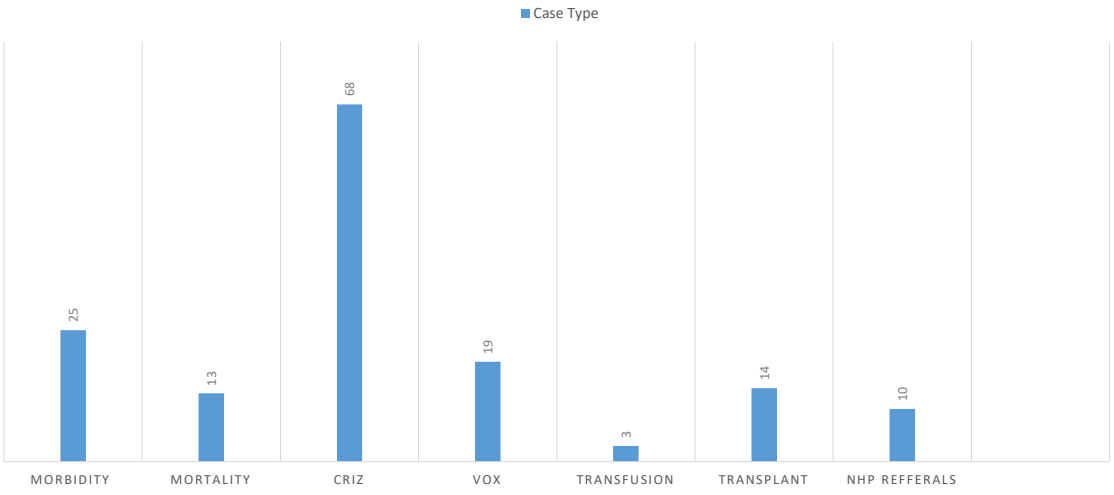
The HCC MDM refers cases as required to the NHP MDM, in line with NHSE policy. We referred 11 cases to the NHP during this period of review. Nine of these were gaining approval for sibling bone marrow transplant according to the eligibility criteria. The other two cases were to review complications of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

Number of cases/Attendees April 22 – March 23



Total Cases: 142
Average Attendees: 12

Type of cases April 2022 – March 23



Fifteen cases were subject to in-depth M&M review during the financial year 2022-23. Individualised learning objectives were identified where appropriate and actioned outside the scope of this report. A summary of key findings is given below:

- Of note is the call for appropriate end-of-life palliative care for patients with sickle cell disorder. Patients with sickle cell conditions often have multiple comorbidities at a younger age. End-of-life care with specific focus for this subgroup of patients should be further explored. During this review year, 5 cases were highlighted where palliative care would have been /was appropriate. One patient was 80 years old; the others were between 49 and 56 years old.

These mortality findings also illustrate that patients with sickle cell have a health status comparable to 70-80 year olds in the general population and justifies further research into optimal management of ageing well.

- 3 cases had some form of intracranial haemorrhage. The findings will be taken into account by the SELSE guideline committee on surveillance for cerebrovascular abnormalities in sickle cell disorder.

- Complications after (long-haul) flights. A new BSH guideline group on flying with sickle cell disorder is being set up.

- A finding not related to M&M outcome was the lack of understanding of Diabetes management of patients with a haemoglobinopathy in the community. Haemoglobin A1c keeps on being used as the gold standard for screening and monitoring (which is not valid in haemolytic anaemias or routinely transfused patients). KCH have introduced a glucose-tolerance test in the haematology day unit. Better information and communication with community service remains paramount in order to avoid suboptimal management of diabetes in patients with a haemoglobinopathy.

8 There was one death that has been raised as a serious incident for further investigation. At the time of publication of this report, the investigation had not yet been completed SELSE HCC Performance

Performance has been reviewed at both HCC and SHT level and is detailed against the NHSE specifications, including both SSQD (Specialised Service Quality Dashboards) and Self Declaration Indicators.

The Network Manager and data manager produce monthly updates for the SHT returns, allowing real time tracking. There are some mitigating factors for the accuracy of this data. The capability for data entry into the NHR came online gradually during 2022-23. For example, there were also delays both in the development of the data entry fields for TCDs and for the capability of TCD providers to access the NHR, so the many of TCDs at the start of the reporting year may not have not been entered on the NHR. Furthermore, the NHR did not complete the mapping exercise of LHTs until April 2022 and the HCC was not able to access the LHT data until this was completed. Therefore, we have not been able to access or enter LHT data. We continue with the monthly review of data collection to identify and issues with data collection.

8.1 HCC SSQD 2022-2023

Indicator	Theme	HCC Indicator 2021-22	Data	Status	Notes
HAEMCC01	Referrals	Number of cases referred to the HCC for specialist discussion	136	✓	
HAEMCC02	Referrals	Proportion of patients that are referred for clinical advice and guidance to the national panel	6	✓	
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	26	✓	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	69	✓	GSTT, LEW, 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	n.a.	✓	Gene therapy not yet available, but many being put forward for HSCT

8.2 SHT SSQD 2022-2023

Indicator	Theme	SHT Indicator 2022-23: 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	84%	✓	
HAEM03i	Pain relief	Percentage of patients given pain relief within half an hour of presentation with sickle crisis, as per NICE guidelines	62%	✓	
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	85%	✓	
HAEM06Ai	Adequacy of chelation	Proportion of eligible patients on long term transfusion who receive cardiac MRI	61%	✓	
HAEM07	Utilisation of Hydroxycarbamide	Proportion of eligible children (> 9 months of age) who are offered Hydroxycarbamide	67%	✓	Only patients currently taking, more than 90% are offered
HAEM08	Utilisation of Hydroxycarbamide	Proportion of eligible adults who are offered Hydroxycarbamide	49%	✓	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)	80%	✓	
HAEM09b	Assessment of modality of regular transfusion programmes	Proportion of regularly transfused adult patients on an automated transfusion programme (simple top-up transfusions)	6%	✓	
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)	20%	✓	
HAEM11b	Assessment of modality of regular transfusion programmes	Proportion of regularly transfused adult patients on an automated transfusion programme (automated exchange transfusion)	94%	✓	

8.3 HCC Self Declaration 2021-2 / 2022-3

HCC – Progress versus Self Declaration Requirements	Status		HCC SELSE
Patient Experience	2021-22	2022-23	**Notes**
The HCC arranges a consistent approach to the formulation of the patient experience exercise which is undertaken at least biennially	✓	✓	21-22 CQI project to respond to issues raised in PREM survey 22-23 To repeat PREM survey
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	✓	✓	Education events completed 2021-22 and further planned for 2022-23
There is a named lead for trans-cranial doppler screenings	✓	✓	HCC SELSE lead – Prof Baba Inusa
The HCC attends national haemoglobinopathy panel meetings	✓	✓	
There are agreed clinical guidelines in place as detailed within the service specification	✓	✓	Notably new guideline on crizanlizumab
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	✓	✓	

8.4 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	✓	✓	

9 Research & Publications

9.1 Clinical Trials

NCT Number	Title	Conditions	Interventions	Characteristics	Population	Dates	Participating Hospitals
NCT03474965 (CSEG101B2201, 2017-001747-12)	**Study of Dose Confirmation and Safety of Crizanlizumab in Pediatric Sickle Cell Disease Patients - SOLACE KIDS**	SCD	Drug: Crizanlizumab	Study Type: Interventional Phase: Phase 3 Study Design: •Allocation: N/A •Intervention Model: Single Group Assignment •Masking: None (Open Label) •Primary Purpose: Treatment	Enrollment: 100 Age: 6 Months to 17 Years (Child) Sex: All	Study Start: October 1, 2018 Primary Completion: June 5, 2023 Study Completion: November 20, 2024	Evelina London Children's Hospital King's College Hospital
NCT03814746 (CSEG101A2301, 2017-001746-10)	**Study of Two Doses of Crizanlizumab Versus Placebo in Adolescent and Adult Sickle Cell Disease Patients (STAND)**	SCD	•Drug: Crizanlizumab (SEG101) •Drug: Placebo	Study Type: Interventional Phase: Phase 3 Study Design: •Allocation: Randomized •Intervention Model: Parallel Assignment •Masking: Quadruple (Participant, Care Provider, Investigator, Outcomes Assessor) •Primary Purpose: Treatment	Enrollment: 240 Age: 12 Years and older (Child, Adult, Older Adult) Sex: All	Study Start: July 26, 2019 Primary Completion: May 30, 2022 Study Completion: December 6, 2027	Evelina London Children's Hospital Guys and St. Thomas' Hospital King's College Hospital
NCT04053764 (CSEG101A2203, 2018-003608-38)	**Study Exploring the Effect of Crizanlizumab on Kidney Function in Patients With Chronic Kidney Disease Caused by Sickle Cell Disease (STEADFAST)**	•SCD •Chronic Kidney Disease	•Drug: Crizanlizumab •Drug: Standard of Care	Study Type: Interventional Phase: Phase 2 Study Design: •Allocation: Randomized •Intervention Model: Parallel Assignment •Masking: None (Open Label) •Primary Purpose: Treatment	Enrollment: 148 Age: 16 Years and older (Child, Adult, Older Adult) Sex: All	Study Start: December 10, 2019 Primary Completion: October 9, 2023 Study Completion: January 20, 2024	Guys and St. Thomas' Hospital King's College Hospital

NCT03763656 (INV543, 2017-004568-37)	**Paediatric Pharmacokinetic study of hydroxyurea**	•SCD •Sickle-Cell; Hemoglobin Disease, Thalassemia •Sickle Cell-betathalassemia •Sickle Cell Hemoglobin C	Drug: Hydroxyrea	Study Type: Interventional Phase: Phase 2 Study Design: •Allocation: N/A •Intervention Model: Single Group Assignment •Masking: None (Open Label) •Primary Purpose: Treatment	Enrollment: 25 Age: 6 Months to 17 Years (Child) Sex: All	Study Start: November 20, 2018 Primary Completion: December 2021 Study Completion: June 2022	Evelina London Children's Hospital King's College Hospital
NCT03975894 (TAPS2version3)	**TAPS2 Transfusion Antenatally in Pregnant Women With SCD**	•SCD •Pregnancy, High Risk •Blood Transfusion Complication	Biological: Serial prophylactic exchange blood transfusion (SPEBT)	Study Type: Interventional Phase: Phase 2 Study Design: •Allocation: Randomized •Intervention Model: Parallel Assignment •Masking: None (Open Label) •Primary Purpose: Treatment	Enrollment: 50 Age: 18 Years and older (Adult, Older Adult) Sex: Female	Study Start: May 2, 2019 Primary Completion: December 1, 2020 Study Completion: May 1, 2022	Guy's and St Thomas' Hospital King's College Hospital
NCT02850406 (GBT440-007)	**Study to Evaluate the Effect of GBT440 in Pediatrics With Sickle Cell Disease (HOPE)**	SCD	Drug: Voxelotor	Study Type: Phase 2a, Design: Open-label, single and multiple dose study	Enrollment: 148 Age: 6-17years Sex: All	Study Start: 05/07/2016 Primary completion: 01/04/2025 Study Completion: 01/04/2025	Evelina KCH
NCT04218084 GBT440-032	**Study to Evaluate the Effect of GBT440 on TCD in Pediatrics With Sickle Cell Disease (HOPE Kids 2)**	SCD	Drug: Voxelotor	Study Type: Interventions Phase: Phase 3 Allocation: Randomized Interventional Model: Parallel assignment Masking: Quadruple Primary purpose: Treatment	Enrollment: 236 Age: 2 to 14years Sex: All TCD: Conditional range	Study Start: 11/11/2020 Primary completion: 24/08/2023 Study Completion: 28/01/2025	KCH Evelina

NCT04188509 (GBT440-038)	**Pediatric Open-Label Extension of Voxelotor**	SCD	Drug: Voxelotor	Study Type: Interventional Phase: Phase 3 Study Design: •Allocation: N/A •Intervention Model: Single Group Assignment •Masking Masking: None (Open Label) •Primary Purpose: Treatment	Enrollment: 50 Age: 4 Years to 18 Years (Child, Adult) Sex: All	Study Start: November 2021. Primary Completion: January 2028 Study Completion: January 2028	Evelina London Children's Hospital King's College Hospital
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

9.2 Other Studies:

9.2.1 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 we are working at setup in Lewisham, Greenwich and 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 will be analysed annually. This project has funding for a five year period but we anticipate that this will be an ongoing project.

To date (July 2023), we have recruited over 450 individuals but are keen to recruit as many as possible to make the results as reflective as possible of our cohort.

In the last year, we have worked with international collaborators in the USA (GRNDaD consortium) on a project comparing outcomes in USA and UK, and hope to extend this partnership going forward.

9.2.2 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 2023.

9.3 Publications

(In chronological order)

Nardo-Marino A, Braunstein TH, Petersen J, Brewin JN, Mottelson MN, Williams TN, Kurtzhals JAL, Rees DC, Glenthøj A. Automating Pitted Red Blood Cell Counts Using Deep Neural Network Analysis: A New Method for Measuring Splenic Function in Sickle Cell Anaemia. Front Physiol. 2022 Apr 5;13:859906. doi: 10.3389/fphys.2022.859906. eCollection 2022. PMID: 35480040 Free PMC article.

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placebo-controlled, double-blind trial of canakinumab in children and young adults with sickle cell anemia. Blood. 2022 Apr 28;139(17):2642-2652. doi: 10.1182/blood.2021013674. PMID: 35226723 Clinical Trial.

Bain BJ, Littlewood T, Rees DC. What does the term 'sickle cell disease' mean? Br J Haematol. 2022 May;197(3):381-382. doi: 10.1111/bjh.18024. Epub 2021 Dec 28. PMID: 34961949 No abstract available.

Stotesbury H, Hales PW, Hood AM, Koelbel M, Kawadler JM, Saunders DE, Sahota S, Rees DC, Wilkey O, Layton M, Pelidis M, Inusa BPD, Howard J, Chakravorty S, Clark CA, Kirkham FJ. Individual Watershed Areas in Sickle Cell Anemia: An Arterial Spin Labeling Study. Front Physiol. 2022 May 3;13:865391. doi: 10.3389/fphys.2022.865391. eCollection 2022. PMID: 35592036 Free PMC article.

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Stotesbury H, Hales PW, Koelbel M, Hood AM, Kawadler JM, Saunders DE, Sahota S, Rees DC, Wilkey O, Layton M, Pelidis M, Inusa BP, Howard J, Chakravorty S, Clark CA, Kirkham FJ Venous cerebral blood flow quantification and cognition in patients with sickle cell anemia. J Cereb Blood Flow Metab. 2022 Jun;42(6):1061-1077. doi: 10.1177/0271678X211072391. Epub 2022 Jan 6. PMID: 34986673 Free PMC article.

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10 Psychology

10.1 Psychology Service for Adults with Sickle Cell & Thalassaemia, King's College Hospital NHS Foundation Trust Annual Report 2022-2023

10.1.1 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 2021 and March 2022.

Provision of the Psychology service was greatly reduced from December 2021, when the lead band 8a Psychologist left his post to take up another role at KCH, though some continuity was achieved by him continuing to work on the Trust Bank system once a week.

A new band 8a Clinical Psychologist was successfully recruited in December 2021 and took up this vacant post from April 2022.

The COVID-19 pandemic continued to have a significant impact upon service provision during this time-period, with the majority of outpatient appointments being primarily telephone based or via online virtual platforms such as Microsoft Teams. Within this time-period, the service has:

- Received 45 new referrals for psychology input and 10 self-referrals, mostly from patients who had already engaged in psychology appointments in the past.
- Seen 37 patients for a psychological assessment.
- Seen 31 patients for an intervention based upon a Cognitive Behavioural Therapy (CBT), Acceptance and Commitment Therapy (ACT) or Interpersonal Psychotherapy (IPT) approach.
- Delivered an 8-week online Interpersonal Psychotherapy (IPT) group attended by 4 patients experiencing symptoms of depression.
- Carried out 3 comprehensive neuropsychological assessments under the specialist supervision of a Consultant Neuropsychologist at KCH.
- Further developed and enhanced the role of psychology within the transition process, in close collaboration with Maria Goridari and Stacey Barkley, Clinical Psychologists in the Paediatric Sickle Cell & Thalassaemia Psychology service.
- Introduced the IMPARTS screening system within the transition clinic, including screening questionnaires to detect symptoms of depression and anxiety and a specific questionnaire to gauge the young person's readiness to take a more active role in managing their own health and healthcare.
- Arranged and attended a further three joint sickle cell and pain clinics.
- Continued to help facilitate the monthly patient support group and provided taught segments on topics of interest, such as overcoming sleep problems and enhancing psychological wellbeing.
- In collaboration with the Psychology team at GSTT and Haemato-Oncology Psychological Therapies team at KCH, continued to contribute to the planning of psychology assessments and support for adult patients with Sickle Cell Disease undergoing Haematopoietic Stem Cell Transplants.

- Delivered a variety of teaching and training events, including:
  - 'Identifying and Responding to the Psychological Needs of Adolescents with Sickle Cell Disease.' Presentation at the British Society of Haematology (BSH) Annual Scientific Meeting on 28th April 2021.
  - 'Mind and Body Interactions in Sickle Cell Disease.' Presentation as part of the SCD Kings College virtual Preceptorship on 17th May 2021.
  - 'The Depressed and Anxious Patient.' Whole day teaching as part of the IMPARTS 5-day course entitled 'Mental health skills for non-mental health professionals.' Delivered on 8th June 2021, 14th September 2021 and 22nd February 2022.
  - 'Psychology Services in Sickle Cell Disease.' Teaching on the Doctorate in Clinical Psychology at Salomons Institute for Applied Psychology, Canterbury Christ Church University on 13th September 2021.
  - 'Psychological Needs of People with Sickle Cell Disease.' Teaching on the Doctorate in Counselling Psychology at the University of East London on 9th February 2022

10.1.2 Service Structure

The service is currently comprised of one 0.8 wte, Band 8a Psychologist, a second post has been unfilled for this financial period:

- Giuliano Sorrentino, Clinical Psychologist, from April 2022
- Post vacant from– April 2022

10.1.3 Current Challenges

As highlighted in previous service reports, demand for the service has continued to grow and staffing levels remain below the ratio of one full-time psychologist to 300 patients (1:300), as recommended by The British Psychology Society's Special Interest Group for Psychologists working with Sickle cell and Thalassaemia. Currently at King's, there are 832 adult patients with a haemoglobinopathy registered, and the lead psychologist is employed 0.8 WTE, resulting in a ratio of 1:1040. To give an idea, similar services in the area with a team comprised of several psychologists have currently an average wait time of up to one year for new referrals to start treatment.

An Honorary Assistant Psychologist post was created in March 2019, and this role is currently filled by U'mau Otuokon, who is making a very significant contribution to the service by conducting telephone screening with some of the new patients referred to the service. U'mau's contract expired last year and has been renewed for another three years in December 2022 (until December 2025).

A band 7 Psychologist has been recruited and is due to start during the summer.

Another very significant problem is lack of desk and clinical space. The lead psychologist is currently working from the following locations:

- Monday. Desk on 4th floor, Hambleden Wing (KCH)
- Tuesday AM. Desk on 4th floor, Hambleden Wing (KCH)
- Tuesday PM. Pod at Caldecott Centre (KCH)
- Wednesday. Working from home.
- Thursday AM. Desk on 4th floor, Hambleden Wing (KCH)
- Thursday PM. Room 8 at Haematology Outpatients (KCH)

The only time the service can see outpatients face-to-face is on Thursday PM, during the Haemoglobinopathies Clinic. This is a very limited time, used for outpatients' appointments, but during which the lead psychologist is also sometimes required to see patients for screening after their clinic appointments with the consultants. On the other days, the service can only see outpatients through either video or telephone call.

Since the lack of desk and clinical space is a problem affecting the department on a broader level, the service has had to build a strong case to counter the pressure coming from the department and be able to keep these spaces. This is likely to become even more problematic once the new Band 7 psychologist will join the team, as they will be employed on a WTE 1.0 basis and there is currently no desk or clinical space allocated to them.

There is a very significant need for adequate facilities within the department to run mental health services. Appropriate clinical space – for either face-to-face appointments or remote work – must be characterised by privacy and quiet, both in order to create a safe environment for the patients and to abide by the professional and ethical code of practice and conduct.

10.1.4 Service provision

The psychology service provides both inpatient and outpatient service.

Psychologists occasionally join the consultant-led haemoglobinopathies ward round, regularly attend weekly multidisciplinary team meetings, and provide psychological support to patients identified as needing input, 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 the psychology service leaflet is sent to them.

Referrals can be initiated by any professional - e.g. consultants, nurses, social worker, GP, etc. - or by the patients themselves. Referrals primarily come from other members of the haemoglobinopathies team, often through introductions to patients at outpatient clinics or during their 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. Decisions on which patients to prioritise are made through assessing them and through collaboration with the rest of the haemoglobinopathies team.

Psychologists will also liaise with GPs - with the consent of the patient - if necessary. In the case of patients who present with risk or safeguarding concerns, the service may breach confidentiality as part of their duty of care.

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.

Between April 2022 and March 2023, 136 patients were referred to the psychology service, and 112 patients received psychological input from the psychology service through at least one of the following:

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

- Face-to-face
- Video conference
- Telephone
- Face-to-face inpatients support or screening for patients admitted to hospital
- Face-to-face screening within outpatient clinic
- Telephone screening
- Support via telephone or email

This resulted in more than 450 individual clinical contacts, in addition to which an additional number of patients were seen through multidisciplinary clinics (the joint Paediatric-Adult Transition Clinic and the joint Pain-Haematology Clinic).

10.1.5 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 lead psychologist was present at these monthly clinics in collaboration with one of the psychologists of the Paediatrics Sickle Cell & Thalassaemia team.

The Joint Haematology-Pain Clinic (ad hoc)

The lead psychologist takes the lead in organising this multidisciplinary clinic, which usually takes place every two or three months.

Patient Support Group

The lead psychologist has attended monthly patient support group meetings alongside other members of the haemoglobinopathies team.

10.1.6 Future Developments

- To complete recruitment process of a new psychologist
- 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
- To resume psychosocial screening for new patients and those having an annual review by reintroducing the use of the IMPARTS screening system and including the ASCQ-Me questionnaires
- Once the new psychologist will have established their role in the service, to consider offering placements and supervision to Trainee Clinical and/or Counselling Psychologists

10.2 The Children and Young People's Sickle Cell & Thalassaemia Clinical Psychology Service, King's College Hospital NHS Foundation Trust Annual Report 2022-2023

10.2.1 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 2022 and March 2023. Within this time frame:

- 56 referrals overall were received and accepted, either for individual psychological assessment and intervention, neuropsychological assessment 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. Dr Stacey Barkley will start shadowing so she can eventually participate as well.
- The new role of Clinical Psychology in the Transition Clinic has been implemented. Both Adult and Paediatric Psychologists have brief, separate from the medical team meetings, with all the patients. 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.
- 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 which was unfortunately cancelled due to strikes. Plans to re schedule.
- Planning and implementation of parent's and young people's groups; Monthly Online Peer Support group for parents and a Tree of Life group for young people.
- Parents in Mind Group; 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. We have run two cycles of this group with having to stop early the second due to non participation.
- 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 a trainee clinical psychologist, with plans for this to continue on a regular rotation.

10.2.2 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.

10.2.3 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)

10.2.4 Current Challenges

- Hybrid model is implemented 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 space for groups for young people and children.
- The above more time than not, dictate whether the psychological intervention will be offered in person or online.
- 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.

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

10.2.5 Direct Clinical Work

A total of 56 new referrals were received by the service between April 2022 and March 2023. The age range: 3 years – 17years.

Fourteen (14) referrals were for a neuro-psychological assessment.

Twenty four (24) referrals were for psychological intervention.

Fourteen referrals for group work and

Four (4) for Consultation Provision to schools.

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

Reasons for referral for psychological intervention - presenting problems;

- Pica symptoms (5 referrals)
- Procedural anxiety - needle phobia (0 referral)
- Generalised anxiety or anxiety related difficulties (8 referrals)
- Adjustment and coping with health condition (9 referrals)

- Frequent pain and pain management (3 referrals)
- Adherence (3 referrals)
- Other (1 referral)
- Tree of Life Group (4 referrals)
- Parents in Mind Group (11 referrals)
- Neuropsychological Assessments (14 referrals)
- Consultation to schools (4 referrals)
- Parent Work (1 referral)
- Ward Emergency (1 referral)

Location/CCG;

- Southwark, 12 cases
- Lambeth, 8 cases
- Lewisham, 11 cases
- Greenwich, 4 cases
- Croydon, 9 cases
- Bromley, 5 cases
- Sutton, 1 case
- Thurrock, 2 case
- Surrey, 1 case
- Plymouth, 1 case
- Rotheram, 1 case
- Enfield, 1 case

10.2.6 Multidisciplinary Clinics

Psychology is present or available in each clinic for:

- Sickle Cell Clinic (Weekly)
- Nurse Led Clinic (Weekly)
- 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.

10.2.7 Teaching and Training

1)
2) "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.

3) "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.
4) 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.
5) Bite size teaching in ED, re psychological aspects of SC

10.2.8 Service Initiatives and Future Developments

- 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.
    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, 16y and above, as well as for patients 16y and below: separate age groups. The former would be in collaboration with Dr Giuliano Sorrentino, Clinical Psychologist in KCH in the Sickle Cell & Thalassaemia Adult Services and Dr Joanna Adebayo and Dr Hannah Grocott, clinical psychologists in Lewisham and Greenwich sickle cell and thalassaemia paediatrics and adult services respectively. The latter with Dr Joanna Adebayo, extended to all South Thames Network.
- Development of rolling Pain Management Group programme for children and young people. Possibility of collaboration with Hatel Bhatt, Counselling Psychologist and Anike Oladejo CAMHS Practitioner, who comprise the psychology service for sickle cell and thalassaemia at Paediatric Liaison Team, St. Thomas', for the Evelina.
- 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.
- Potentially to resolve issues re information governance and start research for using the NIH Toolbox for research.

10.3 Haematology Health Psychology Service Annual Report: Sickle Cell Disease (Adults), Guy's and St Thomas' NHS Foundation Trust 2022-2023

(Note - full version of the report can be found as an attachment)

10.3.1 Summary

This report summarises the sickle cell specific activity for the GSTT Haematology Health Psychology Service (HPS) between 1st April 2022 and 31st March 2023.

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

10.3.2 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 (H&T) 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. 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.

10.3.3 Service Structure

The HPS comprises of:

- 0.6 wte Consultant Clinical/Health Psychologist and Service Lead (Dr Heather Rawle – since 2002)
- 2.0 wte Band 8a Clinical Psychologists (Dr Raselle Miller* – since 2017, Dr Haris Yennadiou* – since September 2019)
- 2.0 wte Band 7 Clinical Psychologists (Dr Abbie Wickham*, Dr Emma Sanchez-Walker*- both since October 2019; Dr Emily Barrasin since March 2020; Dr Kiran Bains since 2021)
- 1.0 wte Senior Assistant Psychologist (Will Tamblyn since September 2021; Sekaylia Gooden – August 2019 – August 2021)
- 0.4 wte Associate Medical Secretary (Tracy Rakshie- since February 2020).

There is also a rolling placement programme for trainees and students.

This is equivalent to **3.4 wte** of qualified psychology service for SCD. The ratio of qualified psychologists to patients is as recommended by national guidelines for Haemoglobinopathy services (1:300).

*maternity leave and secondments have resulted in Dr Georgia Parratt (8a), Emily Barrasin (7) and Ji Park (7) joining the team on fixed term contracts and Dr Abbie Wickham being seconded into 8a role.

10.3.4 Current Challenges and Future Developments

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, have all contributed to an increase in waiting times for outpatient therapy and cognitive assessment. This has increased pressure on staff remaining and reduced the ways in which HPS can get involved in other activities such as developing group programmes, training, research and attending forums of national influence. 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. Various actions have aimed to mitigate the risks including revision of referral criteria, opt-in initiatives, reduction in MDT clinic support and temporary increase in existing staff working hours.

There is scope for expanding the service in all areas, particularly in cognitive assessment. There is also a recognition of the need to protect more senior roles to focus on leadership, service development and overseeing complex case management.

10.4 Paediatric Sickle Cell Disease & Thalassaemia Psychology Service Activity Summary, Guy's and St Thomas' NHS Foundation Trust 2022-2023

10.4.1 Summary

The below information summarises the sickle cell activity for the Children's Psychological Medicine/ CAMHS Liaison Service at St Thomas's Hospital between 01.04.22 – 31.03.23. Within this time frame the service:

- Received a total of 12 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

10.4.2 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 in around mid 2022.

10.4.3 Current Challenges

- Therapeutic assessment and intervention being completed virtually online or over the phone – some families have been struggling with setting up video calls which can delay commencement of sessions or they do not have adequate Wi-Fi to withstand 45-60 minute sessions.
- 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.
- There has been an increase in mental health associated difficulties as schools, families and young people try and get back to their routines. Young people have described worries about going back to school, 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.
- Due to current funding streams, we can experience a delay in funding being approved by local CCG's. This can lead to delay in offering input and dis-engagement from families.
- It has been difficult to organise and arrange on-going support groups. This has been mainly due to poor attendance and engagement to online events and groups.
- Capacity reduced due to limited full time clinicians.

10.4.4 Direct Clinical Work

A total of 12 referrals were received between April 2022 and March 2023 (3 girls; 7 boys, 2 unknown). The average age of the children was 10 to 15 years (age range: 5-17 years). This was a decrease from 37 referrals in comparison to the same timeframe between 2021/2022.

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. We have also had referral related to body image, puberty, and breaking down stigma attached to the diagnosis. All referrals comprised of children & young people within London Boroughs with the majority of referrals being from Lambeth or Southwark catchment areas.

10.4.5 Multidisciplinary Clinics

Psychology is present or available in each clinic for:
Sickle Cell Clinic (Weekly)
Transition Clinic (Monthly)
Haemoglobinopathy MDT (Monthly)

10.4.6 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 more formal assessments of their mental health.

10.4.7 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.

10.4.8 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.

10.4.9 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.

10.4.10 Service Initiatives and Future Developments

- Continued attendance at the British Psychological Society Sickle Cell SIG
- 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
- 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 are hoping to organise a pain workshop group for young people and hope to offer part online and part in person.

Anike Oladejo has just started in the paediatric Liaison Service at St. Thomas, covering the role of Sarah Brennan. Due to the recent changes in staffing in the team, limited information can be available and distributed.

11 Social work

This report details the activity of the Haematology Social work Service at King's College Hospital from 1st May 2022 to 30th April 2023. A full report can be found in the relevant attachment

A total of 185 referrals were received for social work support during the period covered by the report; further data will be presented on disease group/ referral source.

Due to the nature of the work and support provided, many 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 2022- April 2023 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.

12 Staffing

In March 22 due to staffing changes there was an update of HCC roles and responsibilities. These are 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

13 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

14 Attachments

14.1 Full Psychology Report (GSTT) (if appropriate)

GSTT Haematology Health Psychology Annual Report 2022 to 2023.pdf

14.2 Full Psychology Report (LG)

LG Psychology Annual Report CYP and Adults 2022 - 2023.pdf