STSTN ANNUAL REPORT 2019/2020

Contents

1. Introduction

South Thames Sickle Cell & Thalassaemia Network is a haemoglobinopathies collaboration led by healthcare professionals, including consultants, nurses, psychologists and others, across King's College Hospital, Evelina London Children's Hospital and Guy's and St Thomas' NHS Foundation Trusts. We work closely with other hospitals in London and South East England, including University Hospital Lewisham, Queen Elizabeth Hospital Woolwich, and Croydon University Hospital. In total we provide care for over 4000 patients within the network across multiple NHS trusts.

The network includes specialist sickle cell centres within four trusts (Figure 1) and additional acute centres that provide support to patients across South London and South East England (Figure 2).

Figure 1. Specialist Centres of STSTN

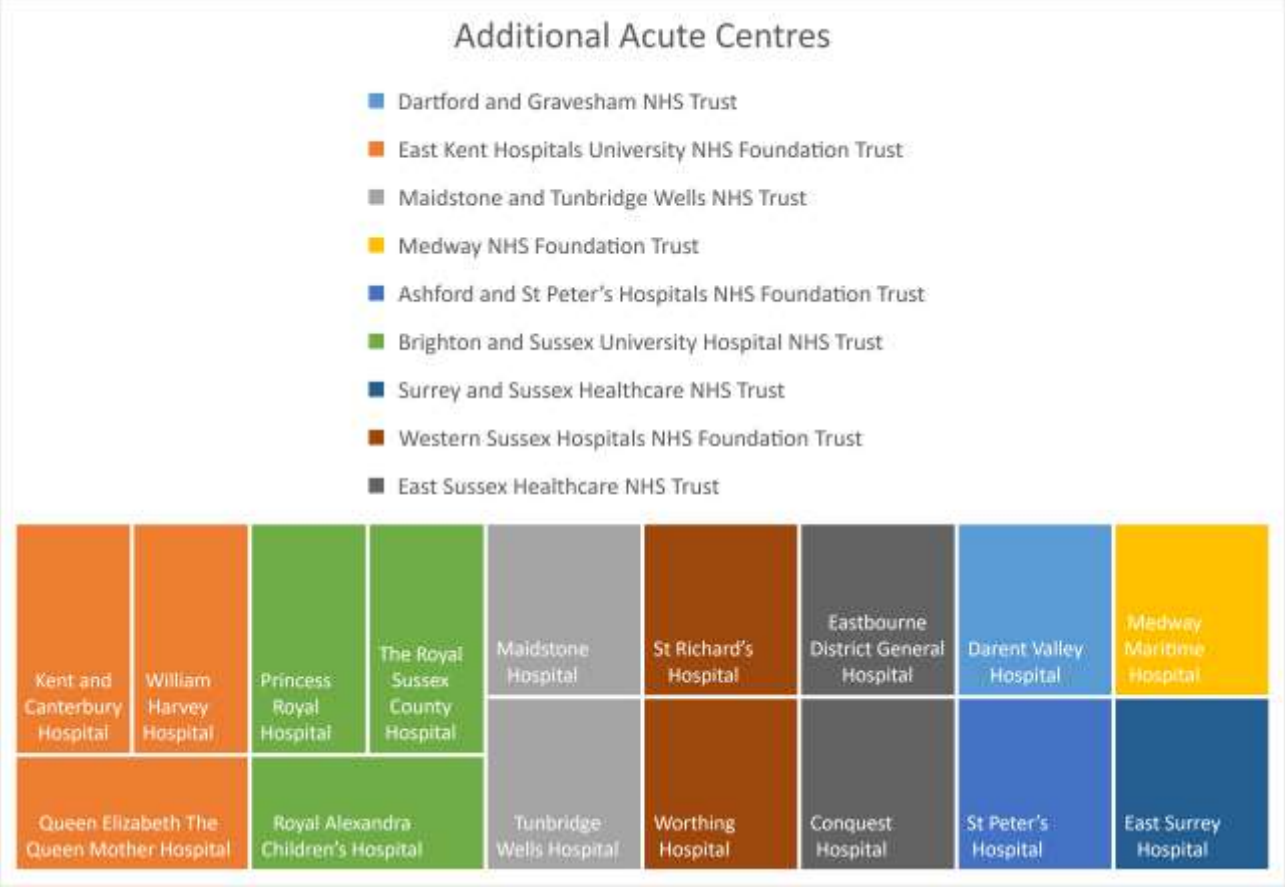


Figure 2. Acute Centres of STSTN

NHS England has now established ten Haemoglobinopathy Coordinating Centres (HCCs) across England to form networks of care to ensure that every child and adult with a haemoglobinopathy has

access to expert clinical management. These HCCs are responsible for ensuring that all patients in the network have annual reviews of care, that transcranial Doppler scans are performed and interpreted appropriately and that expert acute medical care is available locally.

The creation of HCCs should standardise care across the country and allow collection of data to ensure that this is happening.

King's College, Guy's and St Thomas' and the Evelina London Children's Hospitals successfully applied to host the HCC for the south east region. Professor Jo Howard (GSTT), Professor David Rees (KCH), Professor Baba Inusa (Evelina London Children's Hospital) and Dr Moji Awogbade (KCH) were appointed leads of South East London and South East HCC. Our HCC will build upon the strong foundation created by STSTN to continue to improve patient care across our network.

Additionally, a National Haemoglobinopathy Panel (NHP) was created to provide expert, multidisciplinary advice on difficult decisions about the management of patients with sickle cell disease, thalassaemia and some other rare anaemias. KCH, GSTT and the Evelina were also appointed to jointly host this panel, which will work closely with the STSTN and other HCCs across England.

2. Education and Training

To improve the patient experience and ensure that patients receive the same standard of care in all hospitals, STSTN provides an educational programme, produces information resources and provides a peer-support network.

2.1 Educational meetings:

A. Respiratory complications of Sickle Cell Disease (March 2019)

The event consisted of presentations from five consultants across the network, 46 delegates attended.

B. Transition of the patients from the childhood to adulthood (September 2019)

70 delegates expressed interest in the subject, 35 attended.

C. A celebration of Sickle Cell Disease care in South East England: Looking forward to the next decade (January 2020)

The presentations and discussions focused on paediatric sickle cell disease, renal disease in sickle cell disease and obstetric management of sickle cell disease. 54 delegates registered for the meeting and 45 attended.

Feedback from the meetings is displayed in the Table 1.

Overall how would you rate this meeting?	**Very Good**	**Good**	**Quite Good**	**Not very Good**
Meeting A	95.00%	5.00%		
Meeting B	93.00%	7.00%		
Meeting C	65.50%	34.50%		
How did you find out about this meeting?	**Twitter**	**Email Newsletter**	**STSTN Website**	**Word Of Mouth**
Meeting A		85.00%	12.00%	3.00%
Meeting B		41.00%	22.00%	26.00%
Meeting C	41.50%	7.00%	24.00%	27.50%

How satisfied are you with the content of this meeting - programme, speakers?	Excellent	Good	Average	Poor
Meeting A	90.00%	10.00%		
Meeting B	92.50%	7.50%		
Meeting C	72.50%	24.00%	3.50%	
What was your main reason for attending this meeting?	**Education**	**Peer Support**	**Networking**	**Other**
Meeting A	85.00%	10.00%	5.00%	
Meeting B	70.50%	11.00%	18.50%	
Meeting C	69.00%	17.00%	14.00%	

Table 1. Feedback from Educational Meetings

2.2 SpR Training Days

The SpR training day is an educational training day for specialist haematology trainees across the country. There were three educational meetings during the year:

March 2019 – 26 delegates from across the country attended the event.

How satisfied were you:	Excellent	Good	Average	Poor
With the organisation of the course?	100%			
With the venue and facilities?	98%	1%	1%	
Quality of catering?	65%	30%	5%	
With the quality of content and presentations?	95%	5%		

Table 2. Feedback from SpR training day

September 2019 - 21 delegates from across the country attended the event. The overall rating of the course was 98%.

March 2020 – 29 delegates from across the country attended the event. The overall rating of the course was 99%.

2.3 STSTN Red Cell Newsletter

The STSTN red cell newsletter is published twice a year across the network hospitals, the website (www.ststn.co.uk) and social media. It contains information relevant to Sickle Cell and Thalassaemia patients, articles written by patients and news from the STSTN network.

There were two issues (12 and 13) of the newsletter published in 2019. Due to the impact of the COVID19 pandemic, the newsletter planned for July 2020 was published online as an Easter edition with the focus on COVID19. The copies of the publications from years 2019-2020 are attached below (Figure 3).

Issue 12

Red cell news issue 12.pdf

Issue 13

Red cell news issue 13.pdf

Issue 14

Red cell news issue 14.pdf

Figure 3. The issues 12, 13 and 14 of the STSTN Red Cell Newsletter

2.4 Sickle Cell Awareness Day

On 3rd July 2019, to coincide with Sickle Cell Awareness Month, an event was held with the intention of raising awareness, supporting patients and understanding the patients' experience.

It was an occasion for learning and networking for patients, whilst giving professionals a chance to hear from patients about their experiences of living with sickle cell disease and an opportunity for networking and education. The agenda of the event is attached below.

SC Awareness agenda 2019.docx

Figure 4. Sickle Cell Awareness Day Agenda

74 participants attended the event. 33 attendees were associated with Guys and St Thomas and Evelina hospital, 18 were from Kings College, 8 from Lewisham, 5 from Croydon and 1 from Queen Elizabeth hospitals and Sickle Cell society. 10% of attendees were independent of any hospital.
All participants reported finding the event quite good or higher and all groups were largely represented as very satisfied. Presentations and organization appeared to generate the most satisfaction, whilst catering appeared to generate the least satisfaction (Table 3).

How satisfied were you:	Very Satisfied	Satisfied	Neutral	Dissatisfied
With the organisation of the course?	22	7		
With the venue and facilities?	21	6	2	
Quality of catering?	20	6	1	1
With the quality of content and presentations?	23	6		
Structure of the meeting?	18	8	3	
Pace of the meeting?	21	7	1	

Table 3. Feedback from Sickle Cell Awareness Day

2.5 Sickle Cell and Thalassaemia Study Day

Sickle Cell and Thalassaemia Study Day is a haemoglobinopathy training programme for doctors, nurses and allied health professionals that provides eight Continuing Professional Development points from the Royal College of Nursing. The educational day is conducted three times a year and takes place in King's College and Guy's and St Thomas' hospitals. In 2019 84 delegates attended the events. Study days planned for 2020 were cancelled due to the COVID19 pandemic.

2.6 Emergency Department BiTe Size Sessions

BiTe size programme is a training designed to raise awareness of Sickle Cell Disease and Thalassaemia amongst nurses and doctors of the emergency departments. The training consists of four morning sessions and is run three times a year in King's College Hospital. 111 nurses and doctors attended the events in the year 2019/2020.

2.7 Haematology Induction for Nurses

Haematology Induction for Nurses is an induction programme for nurses starting work on haematology wards that includes information on treatment and management of patients with Sickle Cell Disease and Thalassaemia. The training is conducted three times a year in King's College Hospital.

Twenty new haematology nurses attended the events in the year 2019/2020. Similar training was organised for nurses and student nurses from outside STSTN - Kingston Hospital NHS Foundation. 40 nurses and 45 student nurses were trained during the events.

2.8 Theatre Post-Operative Care

Theatre Post-Operative Care is a programme raising awareness of Sickle Cell Disease and Thalassaemia amongst the theatre nurses. The training is conducted twice a year in Kings College Hospital. 22 theatre nurses benefited from the teaching in the year 2019/2020.

2.9 NHSI England Transition Steering Group National Conferences

The aim of the Improving Healthcare Transition Collaborative programme is to improve the transition experiences of young people and staff across the country through the application of quality improvement (QI) methodology and to learn from clinical experts within this field. Within year 2019/2020 NHSI England Transition Steering Group conferences were attended by 150 participants.

2.10 Academy for Sickle Cell and Thalassaemia (ASCAT) conference

The conference was attended by over 350 delegates from Africa, US, EU, Middle East and Australia. A wide variety of topics addressed included:

- Implementation of Newborn Screening for hemoglobinopathies, cohort studies, and the development of management protocols and national control programmes
- New therapies including clinical trials at different stages- Phase I/II/III in sickle cell disease and thalassaemia
- Update on Gene therapies, gene editing and bone marrow transplantation
- Psychosocial aspects including body, mind and health related quality of life in sickle cell disease and thalassaemia
- Blood transfusion including apheresis, iron chelation therapy and acute haemolytic complications
- Quality standards in the diagnosis, treatment of sickle cell and thalassaemia- Global priorities.

ASCAT 2019.pdf

Figure 5. Outcomes of a priority setting workshop with SCD patients and carers

3. Audits

Audits performed within STSTN within last 2 years

3.1 IMPARTS Audit - 2020

The IMPARTS (Integrating Mental and Physical Health Research Training and Services) screening system was introduced at King's College Hospital within haematology clinics in March 2019. Patients attending for an annual review or who are new to the service (e.g. transferred from a different hospital or transitioned from the paediatric service) are invited to complete a series of questionnaires about various aspects of their psychosocial functioning. Patients are given this to complete on an iPad by an Honorary Assistant Psychologist, and scores immediately uploaded to EPR where they are reviewed during the patient's consultation.

Questionnaires used:

- The Patient Health Questionnaire-9 (PHQ-9)
- The Generalised Anxiety Disorder Scale (GAD-7)
- The IRT SMOKING questionnaire
- The Jenkins Sleep questionnaire (JSQ)
- The Work and Social Adjustment Scale (WSAS)
- Brief Pain inventory (for patients who answer that pain been an ongoing and significant problem in their life over the past three months)
- Medication questionnaire (for patients currently prescribed Hydroxycarbamide or Exjade)

Based on completed data up until the 27th February 2020 for 201 patients, the following prevalence rates have been calculated:

- **Depression**
  52 out of 201 patients screened positive for probable Major Depression, a prevalence rate of 26% (based on a score of 10 and above out of 27 on the PHQ-9). This prevalence rate rises to 35% if an additional 19 patients are included who had milder symptoms of depression and scores between 5-9.
- **Anxiety**
  39 out of 201 patients screened positive for probable Generalised Anxiety Disorder, a prevalence rate of 19% (based on a score of 10 and above out of 21 on the GAD-7). This prevalence rate rises to 29% if an additional 19 patients are included who had elevated levels of anxiety and scores between 5-9.
- **Sleep**
  51 out of 201 patients had a high frequency of sleep disturbance, a prevalence rate of 25% (based on a score of 12 or more out of 20 on the JSQ). If using a lower cut of score of 5 and above, this would indicate 68% of patients had experienced poor sleep over the preceding month as compared to normal sleepers.
- **Work and Social Adjustment Scale**
  45 out of 201 patients rated the degree of impairment in their functioning due to their health condition as being in the moderately severe to severe range, a prevalence rate of 22% (based on a score of 21 or more out of 40 on the WSAS). This prevalence rate rises to 52% if those with moderate impairments are included (scores between 10-20 on the WSAS).
- **Pain**
  119 out of 201 said pain had been an ongoing and significant problem in their life over the past three months, a prevalence rate of 59%. Of these 119 patients, 52 said the pain had been in the moderate to severe range over the past week, a prevalence rate of 44% (based on mean scores of 5 and above on the BPI Severity scales), while 60 patients reported the interference of this pain on their life had been moderate to severe over the past week, a prevalence rate of 50% (based on mean scores of 5 and above on the BPI Interference scales).

In reviewing this data it is important to highlight that in other studies depression and anxiety have been shown to be larger predictors of pain factors than disease phenotype, and result in increased frequency, intensity, distress and disruption due to pain (e.g. Levenson et al. 2008).

In this audit, 87% of the patients who screened positive for probable Major Depression said pain had been an ongoing and significant problem in their life over the past three months. This figure was the same for those who screened positive for probable Generalised Anxiety Disorder. Said in a different

way, of the 63 patients with a BPI score of above 55 (moderate to severe pain), 57% also screened positive for probable Major Depression, while 42% screened positive for probable Generalised Anxiety Disorder. These figures lend support for the conclusion that addressing patients' psychological needs through a range of targeted interventions is a vital feature of a multidisciplinary and holistic approach to supporting them to manage their health condition.

The data from this audit is also in keeping with more recent findings that pain in adults with SCD is far more prevalent and severe than previous studies have portrayed (e.g. Smith et al. 2008).

3.2 Hydroxycarbamide Audit – 2019

Hydroxycarbamide is a medication licensed for prevention of recurrent painful episodes in SCD patients. The cohort for audit of uptake of hydroxycarbamide were patients attending STSTN hospitals with genotypes HbSS and HbSb^{o} excluding patients on transfusion program (Figure 6) and assessing criteria were British Society for Haematology Guidelines from May 2018.

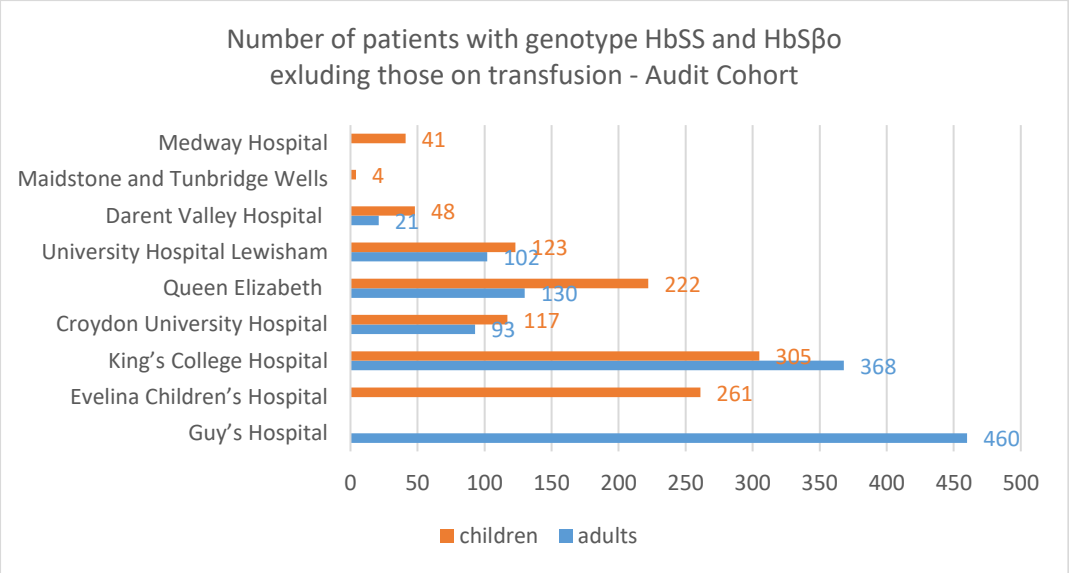


Figure 6. The number of patients with genotype HBSS and HbSβ^{o} excluding those on transfusion for STSTN

The BSH guidelines may have increased awareness and helped to drive increased Hydroxycarbamide provision and uptake. Between 20% and 52% of eligible patients are on hydroxycarbamide across STSTN hospitals. The use of hydroxycarbamide by patients with SCD has increased in most units between 2017 and 2019 (Figure 7 and 8), however the wide range in hydroxycarbamide uptake in STSTN hospitals suggests inequity of provision.

The drawbacks of the audit were:

- Not all patients listed as being on hydroxycarbamide are compliant
- NHR shortcomings
- Duplicate entries, incomplete data, discrepancy in active and inactive patient definition and degree of accuracy in maintaining and updating hospital entries
- No clear target for hydroxycarbamide uptake
- Some milder forms of SCD e.g. HbSC on hydroxycarbamide or transfusion
- Some patients attending more than one site were possibly double counted
- Some patients are not regular attendees at any site and therefore were not represented.

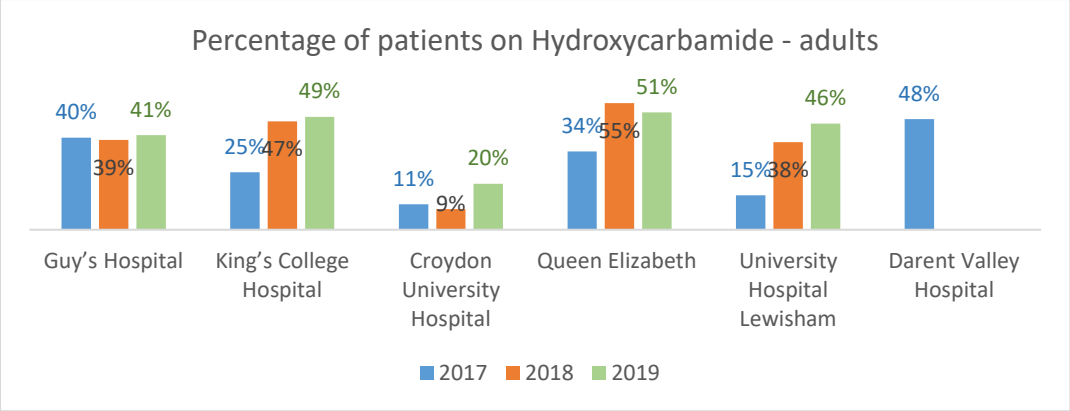


Figure 7.Results of the Hydroxycarbamide audit -the percentage of adult patients on Hydroxycarbamide within STSTN for years 2017, 2018 and 2019.

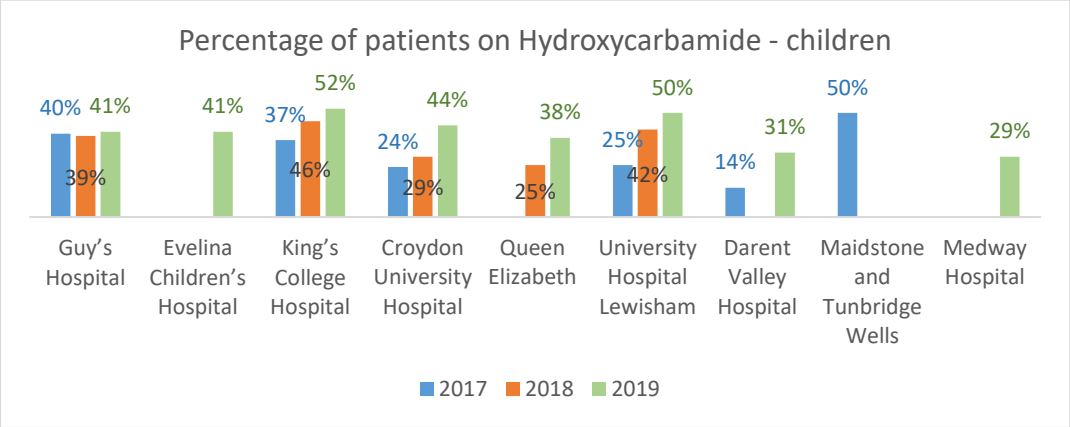


Figure 8. Results of the Hydroxycarbamide audit - the percentage of paediatric patients on Hydroxycarbamide within STSTN for years 2017, 2018 and 2019.

3.3 Compliance with BSH guideline for management of Acute Chest Syndrome in Sickle Cell Disease Audit – 2019

The aim of the audit was to determine whether Acute Chest Syndrome is being appropriately diagnosed, investigated and treated in patients with Sickle Cell Disease in STSTN hospitals.

The data for the audit came from patients with male to female and adult to paediatric ratios of 1:1. All the patients presented with the chest pain and the sickle genotypes were HbSS (90%) and HbSC (10%). The age range was 4-53 years with median of 17 years. STSTN network hospitals performed well, however certain areas (values highlighted in red in Table 4) require improvement.

Audit parameter	KCH	GSST	Evelina	Croydon	LGT
Clinical observation 4-hourly	70%	21%	85%	80%	97%
Chest examined daily	100%	62%	78%		85%
Low O2 sats escalated	100%	83%	26%	100%	100%
Blood culture	100%	100%	100%	50%	50%
Blood transfusion	100%	100%		80%	100%
CXR, FBC,Biochemistry, G&S	100%	100%	100%	100%	100%
ABG	100%	100%		100%	100%
Sputum/NPA	100%	80%	40%	30%	100%
Fluids	100%	100%	100%	90%	100%

Appropriate antibiotics	100%	100%	100%	100%	100%
Physio, incentive spirometry or bubble play	100%	100%	75%	80%	100%
Analgesia	100%	100%	90%	100%	100%
ICU/HDU review if appropriate	100%	100%	100%	100%	100%
Bronchodilators if wheezing	100%	100%	100%	100%	100%
Oxygen therapy prescribed	100%	100%	100%	100%	100%
HC considered in severe or recurrent cases	HU 60%	HU 4		60% children	
	no data 40%	EBT 1		1 adult	
		HU increase 1			
		HU restart 1			
Route of admission	ED 60%	ED x 4	ED 95%	ED	EDx2
	PICU 30%	DU x 1	PICU 1		
	HOP 10%				

Table 4.The results of Compliance with BSH for STSTN

Recommendations for improvement:

- Improve observation frequency and documentation especially between hours 00:00-0600am
- Document daily chest examination
- Improve access to incentive spirometry
- Target ACS and admission cases to offer HC treatment and document discussions
- Clarify audit questions.

Action plan:

- Present audit at network and local meetings
- Celebrate successes
- Haematology ward nurse teaching regarding essential regular observations
- Improved HC access
- Shared decision making tool
- Update STSTN guidelines
- Update STSTN HC patient information
- Re-audit November 2020.

3.4 Sickle Cell Disease Acute Pain Episode Audit - 2018

Audit of management of sickle cell disease patients presenting with acute pain to all STSTN Emergency Departments and Specialist Day Centres between 09:00 on 12/02/2018 and 09:00 on 19/02/2018. Audit sample included adults, young people and children presenting to STSTN hospitals with a sickle cell acute painful episode and the standards were based on NICE clinical guidelines for sickle cell acute painful episodes.

76 audit data collection forms were completed for 24 children and 52 adults. Amongst the participants, 33 were male, 42 female and gender of one was not specified. The age range was 1-63 years with mean age of 25.7 years. Most STSTN hospital sites provided returns, however sites with fewer patients might have experienced no episodes of acute pain presentation by patients within a 7-day audit period.

STSTN network hospitals performed well (Figure 9) and met local target:

- 100% had pain assessed at presentation to hospital
- 99% of those presenting in pain received analgesia within 30 minutes
- 99% with appropriately measured observations at presentation
- 93% received oxygen supplementation if their oxygen levels were <95%
- 96% reporting moderate or severe pain received a bolus of strong opiate
- 0% offered pethidine.

However,

- 18% of patient did not have pain assessed every 30 minutes until controlled
- 13% did not have pain assessed every 4 hours thereafter
- 38% were not offered laxatives, if taking an opioid
- 19% were not offered paracetamol
- 22% were not offered ibuprofen
- Only 11% seen in support unit/outpatient setting, other 89% seen in ED
- 88% clinically assessed every 1 hour in first 6 hours when taking strong opioids
- 93% clinically assessed at least every 4 hours once stable, if taking strong opioids.

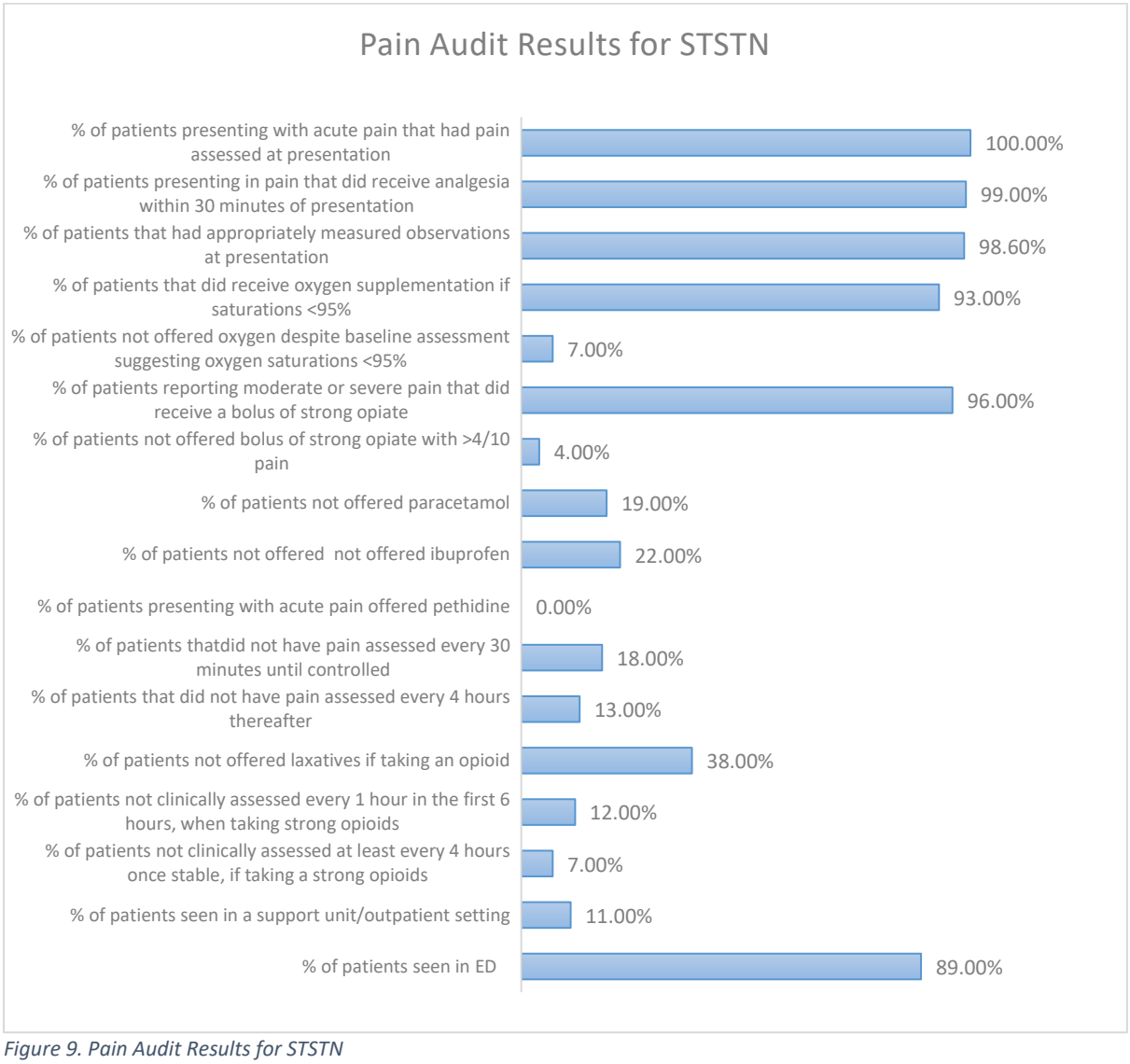


Figure 9. Pain Audit Results for STSTN

The unexpectedly small number of audit returns from each centre suggests that not all episodes were recorded. The next audit period will be extended to two weeks. Agreed target for next audit to be repeated every February is 90%. The NICE data collection tool left scope for ambiguous responses, hence the tool will be amended for 2020 audit.

4. Covid19 Statistics for STSTN

There were 66 cases (Table 5) of COVID19 positive patients reported within the STSTN network between 01.03.2020 and 23.06.2020. The patients were aged between six months and 72 years with mean age of 37.44 years. 69.70% of cases were female and the mortality rate calculated over investigated time period was 4.76%.

Hospital	Number of COVID19+ patients
Croydon University Hospital	2
Evelina Children's Hospital	1
Guy's and St Thomas	26
Kings College Hospital	31
Princess Royal University Hospital	1
Queen Elizabeth Hospital, Woolwich	1
University Hospital Lewisham	4
Total	**66**

Table 5. Number of COVID19 positive patients within STSTN

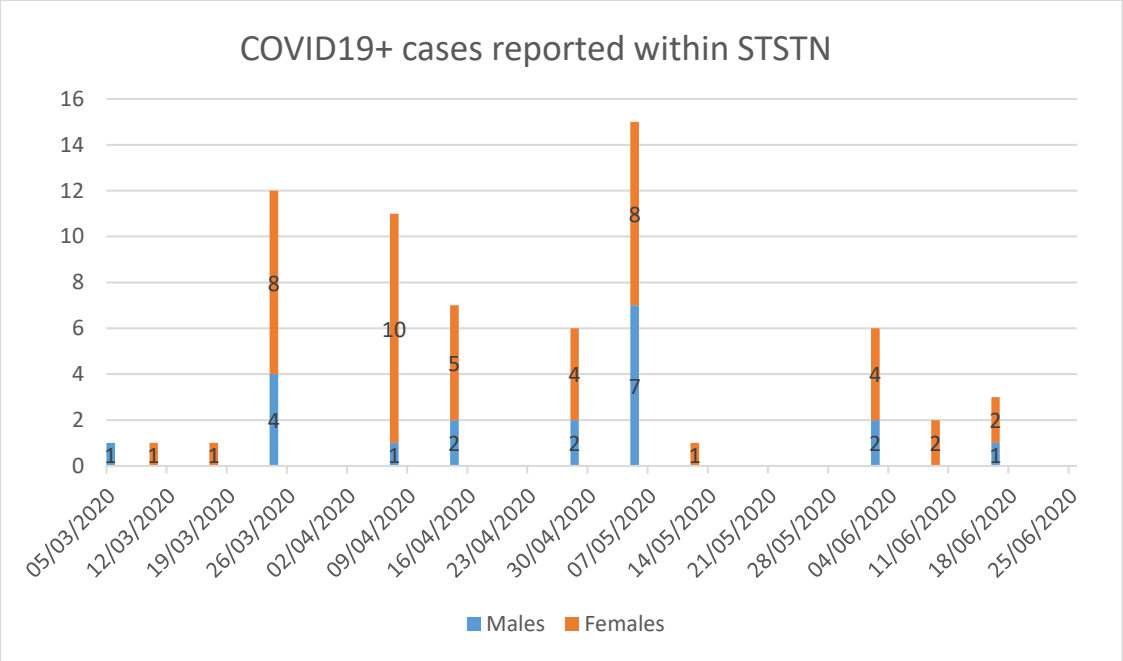


Figure 10. Number of COVID19 positive patients within STSTN over investigated time period stratified by gender

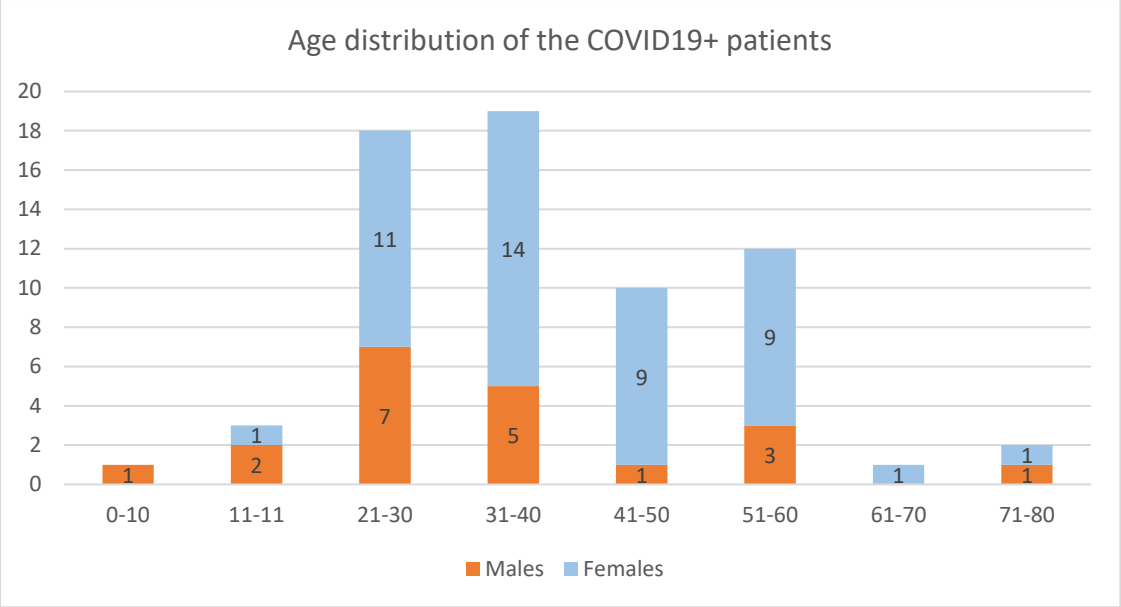


Figure 11. Age distribution of COVID19 positive patients within STSTN stratified by gender

5. Psychology

5.1 Psychology Service for Adults with Sickle Cell & Thalassaemia, King's College Hospital NHS Foundation Trust Annual Report 2019-2020

– full version of the report can be found in the Appendix

Summary

This report summarises the activity of the Psychology Service for Adults with Sickle Cell & Thalassaemia based at King's College Hospital between April 2019 and March 2020. Within this time frame the service has:

- Seen a total of 82 patients for individual psychological assessment, and of these, 43 were seen for an intervention;
- Introduced the IMPARTS screening system into haematology clinics to assess the psychosocial needs of patients attending for an annual review or who are new to the service, in order to identify the type of help they may need;
- Carried out cognitive assessments of five patients and continued to develop referral pathways for patients with neuropsychological needs;
- Arranged a further four joint sickle cell and pain clinics at which there was 100% attendance. Four patients went on to have joint follow up appointments with the team psychologist and a pain CNS;
- Reached a point at which psychology appointments will be recorded on the electronic patient booking system (PIMMS) so that a tariff and payments can be attached to these appointments;
- Delivered a variety of teaching and training events;
- Regularly attended and contributed to South Thames Sickle Cell & Thalassaemia Network meetings and events.

Service Structure

The service is currently comprised of:

- Gary Bridges, Counselling Psychologist (0.8 wte, Band 8a)
- U'mau Otuokon, Honorary Assistant Psychologist (0.1 wte)

Current Challenges

Demand for the service continues to grow and staffing levels remain below the ratio of one full time psychologist to 300 patients, as recommended by The British Psychology Society's Special Interest Group for Psychologists working in Sickle cell and Thalassaemia. Currently at King's, there are 675 adult patients with a haemoglobinopathy registered, and the team psychologist is employed 0.8 WTE, resulting in ratio of 1:844. Ways of increasing capacity to see patients continue to be investigated and pursued, such as taking on a trainee clinical, counselling or health psychologist, but ultimately an additional psychologist is required to ensure that the clinical need can be met and the remit of the service extended. An Honorary Assistant Psychologist post was created in March 2019, with a specific remit to assist with the implementation of the IMPARTS screening system in the Thursday afternoon clinic, and this role is currently filled by U'mau Otuokon.

The demand for the joint sickle cell and pain clinics is also high, with a waitlist having developed. Results of the IMPARTS screening confirm that significant numbers of patients experience pain that is a persistent problem and which causes significant disruption to their lives. The demand for this clinic indicates the need for this to be at least a bimonthly clinic with four patients attending each one.

The COVID-19 pandemic began to significantly impact upon service provision during March of 2020, with patients being instructed to engage in social shielding and face-to-face outpatient appointments stopped. The psychology service has had to adjust rapidly to new ways of working, including patient contacts primarily being shifted to being telephone based or via online virtual platforms.

Future Developments

- Develop online and virtual ways of delivering psychological interventions in light of the ongoing COVID-19 pandemic and restrictions on face-to-face patient contacts.
- Extend the IMPARTS screening system to use it as an outcome measure for psychological interventions.
- Extend the remit of the psychology service so that in addition to carrying out relatively brief cognitive assessments, more detailed assessments can be conducted with instruments such as the Wechsler Adult Intelligence Scale—Fourth Edition (WAIS-IV), and specialist supervision provided by a Consultant Neuropsychologist from King's.
- Introduce the IMPARTS screening system into the joint sickle cell and pain clinics in order to further assess psychological and behavioural responses to pain, and create workshops on developing ways of managing persistent pain for patients to attend afterwards.
- Develop and enhance the role of psychology within the transition process, in close collaboration with Maria Goridari, Clinical Psychologist in the Paediatric service, and Giselle Padmore-Payne, Roald Dahl Transition and Senior Haemoglobinopathy Clinical Nurse Specialist. Aims include the creation of psychology information leaflets for patients attending the transition clinic and the introduction of the IMPARTS screening system with a specific questionnaire to gauge the young person's readiness to take a more active role in managing their own health and healthcare, and develop a rolling Tree of Life programme for transition aged patients.
- Continue attendance at the British Psychological Society Sickle Cell and Thalassaemia SIG, and contribute to the ongoing development of shared good practice.

- Offer placements and supervision to Trainee Clinical and/or Counselling Psychologists.
- Develop a business case for increased psychology provision within the service, linked to appointments being assigned a tariff and therefore being income generating.

5.2 The Children and Young People's Sickle Cell & Thalassaemia Clinical Psychology Service, King's College Hospital NHS Foundation Trust Annual Report 2019-2020

– full version of the report can be found in the Appendix

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 May 2019 and March 2020. Within this time frame the service:

- Between May 2019 and January 2020 the post was vacant.
- Middle January 2020, Maria Goridari, Clinical Psychologist, was appointed.
- In February and March, 12 referrals were received for individual psychological assessment and intervention.
- Regularly attended and contributed to BPS Specialist Interest Group.
- Tried to put together waiting list for neuro psychological assessment referrals, so the clinic could start running again.

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

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 the post was vacant. A new Clinical Psychologist was appointed in middle January 2020, and began accepting referrals in February 2020. The service is currently comprised of:

Maria Goridari (1.0 wte, Band 8a)

Current Challenges

- Very soon after the appointment of the new clinical psychologist, the COVID-19 pandemic broke out. Following that, the service had to adjust to new ways of working, new demands and new measures put in place.
- In person clinics and meetings were put on halt. Clinics shifted to phone clinics and meetings were reviewed for the initial period.
- Due to the above, referrals slowed down. All cases referred, accepted and open had to shift to either phone or online consultation instead of in person, outpatient appointments.
- Neuro psychological assessments had to be put on halt until further guidance from regulatory and professional bodies and from Trusts and government, with regards to in person outpatient or other appointments.

- It is expected for the referrals to increase; 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. The increase in referrals was reflected in the previous report (2017). It is expected to be a challenge to balance and manage the demands, especially having one psychologist only in post.
- Current changes in the structure of the "Children & Young People's Sickle Cell & Thalassaemia Clinical Psychology Service" under the N & S CAMHS Service. Discussions are ongoing and communication is open between King's College Hospital Haematology Team and SLaM to best address these changes and the impact on the service.

Consideration is required to ensure that clinical need continues to be met and the impact of this increase on service efficiency and efficacy.

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.
- 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.
- Development and contribution to BPS SIG sub-group, with specific interest in paediatric neuropsychological screening.
- Development of psychosocial information leaflets for patients in the Transition Clinic – over 16y. Development and enhancement of the role of the psychologist in the transition clinic in close collaboration with Dr Gary Bridges, Clinical Psychologist, and Giselle Padmore-Payne, Senior Clinical Nurse Specialist and Team Lead for Adult Haemoglobinopathies, in the Adult Service, including the introduction of the IMPARTS screening system with a specific questionnaire to gauge the young person's readiness to transition to the adult service and take a more active role in managing their own health and healthcare.
- Development of rolling Tree of Life programme for patients and parents, in the future in collaboration with the Adult Service; Dr Gary Bridges, Clinical Psychologist, and Giselle Padmore-Payne, Senior Clinical Nurse Specialist and Team Lead for Adult Haemoglobinopathies.
- Thoughts about future, possible placement and supervision to Trainee Clinical Psychologists.
- Develop business case for increased psychology provision within our service.

5.3 Haematology Health Psychology Service Annual Report: Sickle Cell Disease, Guy's and St Thomas' NHS Foundation Trust 2019-2020

– full version of the report can be found in the Appendix

Summary

The report summarises the activity for the GSTT Haematology Health Psychology Service (HPS) for Adults with Sickle Cell & Thalassaemia between 1st April 2019 and 31st March 2020.

The report focusses on four core service objectives:

- Specialist psychological support for patients and significant others
- Staff support, training and consultation
- Promotion and improvement of psychological aspects of haematology services at a local and national level
- Specialist trainee and student placements

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. 76% of referrals to the HPS are patients with sickle cell disease (SCD). The service expanded most recently in 2019 following a successful business case.

The HPS was the first in the UK to provide dedicated psychological support to people with SCD. It is mainly located within the haematology department at Guy's Hospital and is therefore well integrated within the multidisciplinary haematology teams*. It also provides some integrated care to the Centre for Haemostasis and Thrombosis at St Thomas' Hospital. We see inpatients and outpatients and offer individual evidence-based psychological therapy, group therapy/support, cognitive assessment, and joint multidisciplinary consultations. 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.

Service Structure

The HPS comprises of:

0.6 wte Consultant Clinical/Health Psychologist and Service Lead (Dr Heather Rawle – since 2001)
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)
1.0 wte Senior Assistant Psychologist (Sekaylia Gooden – since August 2019)
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).

Current challenges and future developments

In March 2020, the impact of the global pandemic COVID19 became apparent for the UK. This has had profound effects on service delivery and patient experience. All patient contact was moved to virtual methods, an increase in patient and staff support has been necessary to address the additional challenges that COVID19 presents, and a rota was instigated for staff to work from home for part of the week.

COVID19 has presented the HPS with an opportunity to re-evaluate how services are delivered in order to ensure continued accessibility, particularly for those patients who are most vulnerable. Virtual appointments have greatly reduced DNA rates and virtual support group has resulted in increased attendance. We are surveying patients' preferences regarding modes of contact with psychology and therapy delivery and are searching for IT solutions so that group webinars and improved virtual support groups can be offered. We are exploring how annual review/therapy measures can be completed virtually. However it is important that face-to-face contact can be resumed for patients whereby this is clinically indicated (e.g. new appointments, trauma work, cognitive assessments) or

preferred by patients. It is also important to maintain the visibility and accessibility of the HPS (for staff and patients) despite the necessity of part remote working for all staff members and this has so far been achieved by ensuring attendance at the more frequent virtual team meetings.

An additional ongoing challenge is office and therapy space – this limits patient appointments and capacity to take on Doctorate trainees and students.

5.4 Pediatric Sickle Cell Disease & Thalassaemia Psychology Service Activity Summary, Guy's and St Thomas' NHS Foundation Trust 2019-2020

Summary

Summary of the sickle cell activity for the CAMHS Paediatric Liaison Service at the Evelina London Children's Hospital between 01.04.19 – 31.03.20. Within this time frame the service:

- Nineteen referrals for individual psychological assessment and intervention
- Monthly transition clinics co-facilitated with the adult sickle cell psychology service based at Guys Hospital
- Clinical consultation as part of weekly outpatient sickle cell clinics at Evelina London Children's Hospital.

Background and 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 post who provides clinical consultation and direct clinical assessment/intervention to the paediatric sickle cell and thalassaemia team at the Evelina London Children's Hospital over a total of 3 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.

This clinical position has largely been filled by Hatel Bhatt Counselling Psychologist (1.0 wte) who is currently on maternity leave until March 2021. Since March 2020 this position has been filled by Sarah Brennan, senior occupational therapist (Band 7). Recently the posts of band 7 neuropsychologist (0.5 wte) and band 7 psychologist (1.0 wte) were approved.

Current challenges:

- Impact of Covid-19 and lockdown restriction measures on direct clinical assessment and intervention
- Outpatient clinics being completed virtually or over the phone – some families having difficulty with technology at home or do not have access to computers or smart phones
- 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.
- COVID has created an added complexity when completing clinical intervention around anxiety in relation to living with a chronic medical condition – difficult to consistently administer and monitor CBT techniques (eg. Behavioural activation) when a young person's everyday life routine has significantly changed due to lockdown and them being within the shielded category. Their anxieties around becoming unwell due to coronavirus are an additional significant worry for them and has been a predominant theme throughout sessions.

- A reduction in clinical referrals throughout recent months which appears to be directly in line with a reduction in sickle cell acute hospital admissions. Families have provided account of managing pain episodes at home due to being fearful of attending hospital settings due to coronavirus.
- The indirect impact of Hatel Bhatt going on maternity leave and a delay in recruitment during the first quarter of 2020.

Direct Clinical Work:

A total of 19 referrals were received between 1st April 2019 – 31st March 2020 (12 girls; 7 boys). The average age of the children was 11-12 years (age range: 4-14 years). There was a reduction in referrals in comparison to the same timeframe between 2018/2019 (31 referrals) which could be understood in the context of the above challenges. Children and young people were referred to the service for a variety of reasons including assessment and intervention in relation to pain management, depressive and anxious symptomatology associated with living with a chronic medical condition and pica behaviours. The referrals mostly comprised of children & young people within London Boroughs (17) and the remaining 2 referrals were based within the CCG areas of Milton Keynes and Berkshire.

Service Initiatives and Future Developments:

- 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
- Development of psychosocial information leaflets for patients and families
- Placements and supervision for Trainee Clinical Psychologists.

6. Haemoglobinopathy dashboard collated for STSTN

Haemoglobinopathy dashboard for HCC		KCH		GSST		Croydon		Lewisham
		Children	Adults	Children	Adults	Children	Adults	Children &Adults
HAEM02	Number of children having TCD monitoring within national guidelines.	214		240		52		144
	Total number who are eligible for TCD monitoring.	227		260		58		175
	%	94.27%		92.31%		89.66%		82.29%
HAEM03i	Number of patients given pain relief within half an hour of presentation with Sickle crisis as per NICE guidelines		25	8	19	79	51	38
	Total number of events (patients presenting with Sickle crisis) within reporting period		26	14	36	96	199	69
	%		96.15%	57.14%	52.78%	82.29%	25.63%	55.07%
HAEM04A	Number of patients entered onto care pathway	11		21		12		16
	Total number of identified patients within reporting period	11		21		12		16
		100%		100%		100.00%		100.00%
HAEM04B	Number of children beginning Penicillin at or before 3 months of age as per screening programme guidelines	11		21		11		15
	Total number of children eligible to begin Penicillin within reporting period	11		21		11		15
	%	100%		100%		100.00%		100.00%
HAEM05	Number of annual reviews undertaken by the centre as recorded by NHR entry within that year	295		301	610	129	133	569
	Total number of registered patients eligible for annual reviews on NHR by that centre	370		450	679	152	146	739
	%	79.73%	92.3%*	66.89%	89.84%	84.87%	91.10%	77.00%
HAEM06Ai	Number of eligible patients (adults and children) on long term transfusion patients who receive cardiac MRI	9	47	3	7	N/A	N/A	10
	Total number of patients (adults and children) eligible for cardiac MRI within reporting period	18	52	3	7	N/A	N/A	23
	%	50.00%	90.38%	100.00%	100.00%	N/A	N/A	43.48%
HAEM06Aii	Number of those who had MRI who achieved figure more than 20 ms	9	42	4	6	N/A	N/A	10
	Total number of patients who received cardiac MRI within reporting period	9	47	4	7	N/A	N/A	10
	%	100.00%	89.36%	100.00%	85.71%	N/A	N/A	100.00%
HAEM06Bi	Number of eligible patients who receive MRI for liver iron- SICKLE only	8	42	40	22	N/A	N/A	7
	Total number of transfused/chelated patients supervised by centre eligible to have MRI for liver iron within reporting period - SICKLE only	17	46	40	22	N/A	N/A	20
	%	47.06%	91.30%	100.00%	100.00%	N/A	N/A	35.00%

HAEM06Bii	Number of those who had MRI who achieved less than 7 mg/gm/DW liver iron - SICKLE only	7	22	24	11	N/A	N/A	2
	Total number of patients who received MRI for liver iron within reporting period - SICKLE only	8	42	40	22	N/A	N/A	7
	%	87.50%	52.38%	60.00%	50.00%	N/A	N/A	28.57%
HAEM06Ci	Number of eligible patients who receive MRI for liver iron - THALASSAEMIA only	1	5	4	5	N/A	N/A	3
	Total number of transfused/chelated patients supervised by centre eligible to have MRI for liver iron within reporting period - THALASSAEMIA only	1	7	4	5	N/A	N/A	3
	%	100.00%	71.43%	100.00%	100.00%	N/A	N/A	100.00%
HAEM06Cii	Number of those who had MRI who achieved less than 7 mg/gm/DW liver iron - THALASSAEMIA only	0	2	0	4	N/A	N/A	2
	Total number of patients who received MRI for liver iron within reporting period - THALASSAEMIA only	1	5	4	5	N/A	N/A	2
	%	0.00%	40.00%	0.00%	80.00%	N/A	N/A	100.00%

Table 6. Haemoglobinopathy Dashboard collated for STSTN

* 92.3% of adult patients had an Annual Review (ARV) between 1st of April 2019 and 31st of March 2020. No ARV were carried out in March 2020 due to the pandemic. Annual reviews for adult haemoglobinopathy patients were not routinely entered on to the NHR after the haemoglobinopathy data manager left in early 2019. This issue is now being addressed.

7. Research

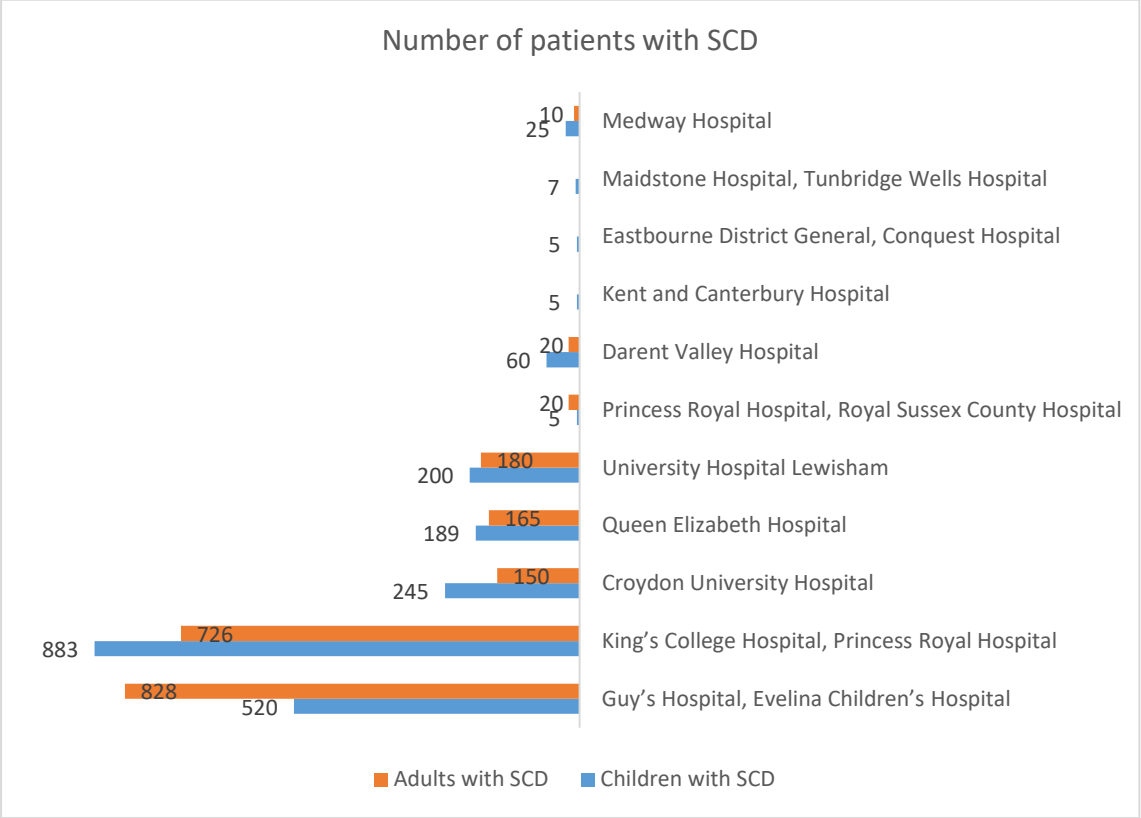
Clinical trials conducted within STSTN are listed in Table 7.

Trust	Study	Number of Patients Recruited
Guy's and St Thomas' NHS Foundation Trust:	ACZ885	1
	BioResource	9
	GBT440-007	2
	GBT440-034	2
	Hestia 3	3
	IMR-SCD-102	2
	INV543 HUPK	4
	LA38-EXT	2
	STAND	2
King's College Hospital NHS Foundation Trust:	GBT 440-034	1
	IMR-SCD-102	9
	INV543	2
	SOLACE CSEG101B2201	3
Lewisham and Greenwich NHS Trust:	IMR-SCD-102	5
Croydon Health Services NHS Trust:	IMR-SCD-102	10
Total		57

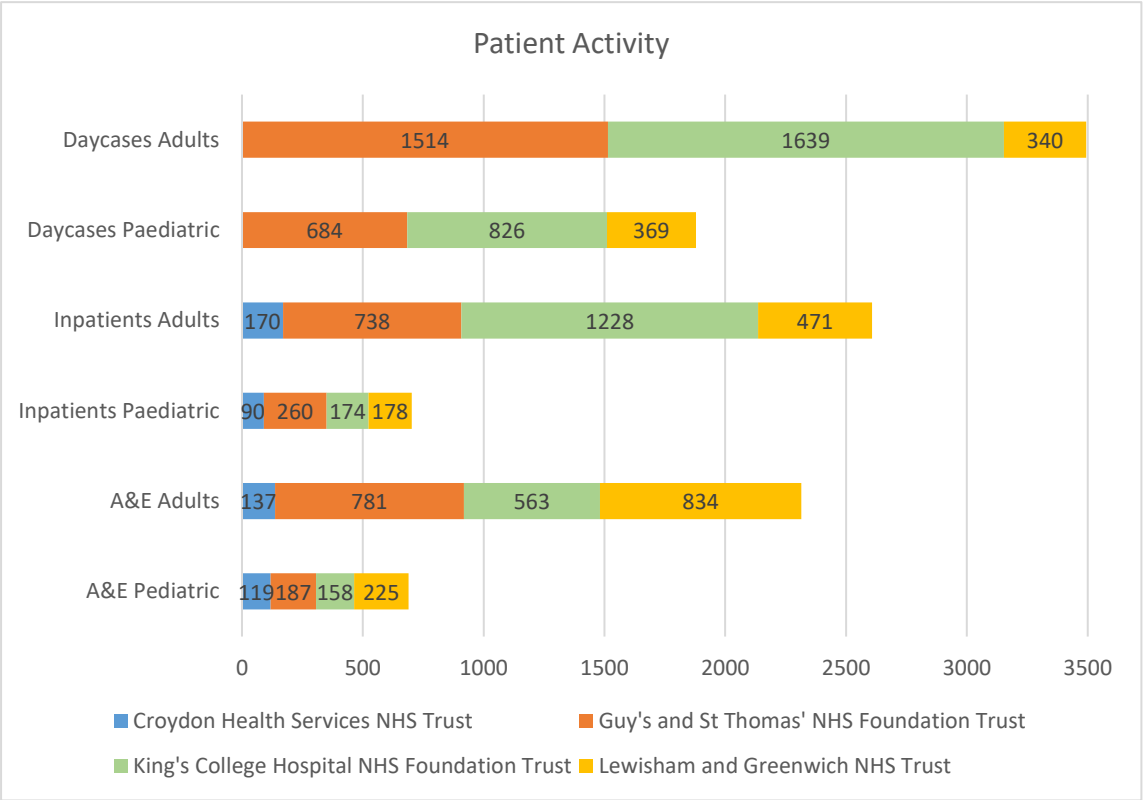
Table 7. The Clinical Trials within STSTN

8. STSTN chosen statistics

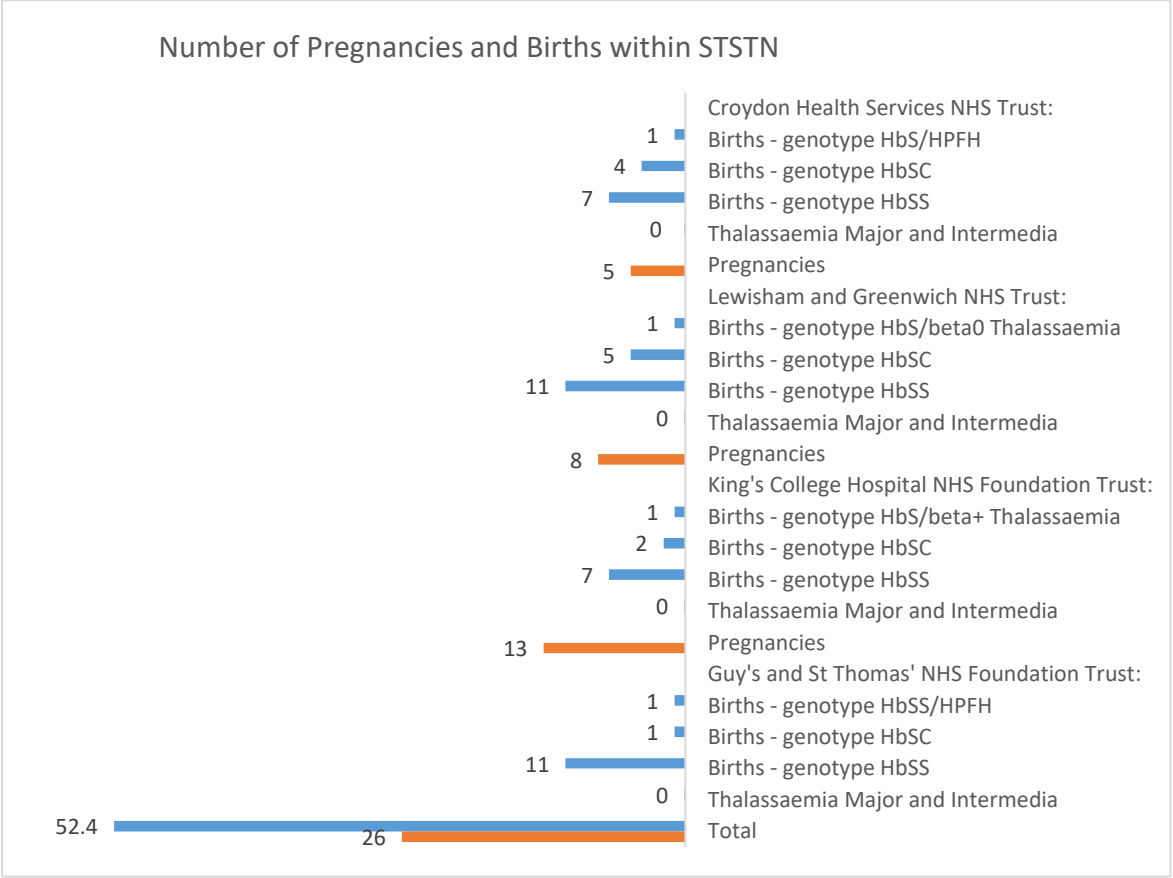
8.1 Number of patients with Sickle Cell Disease within STSTN network



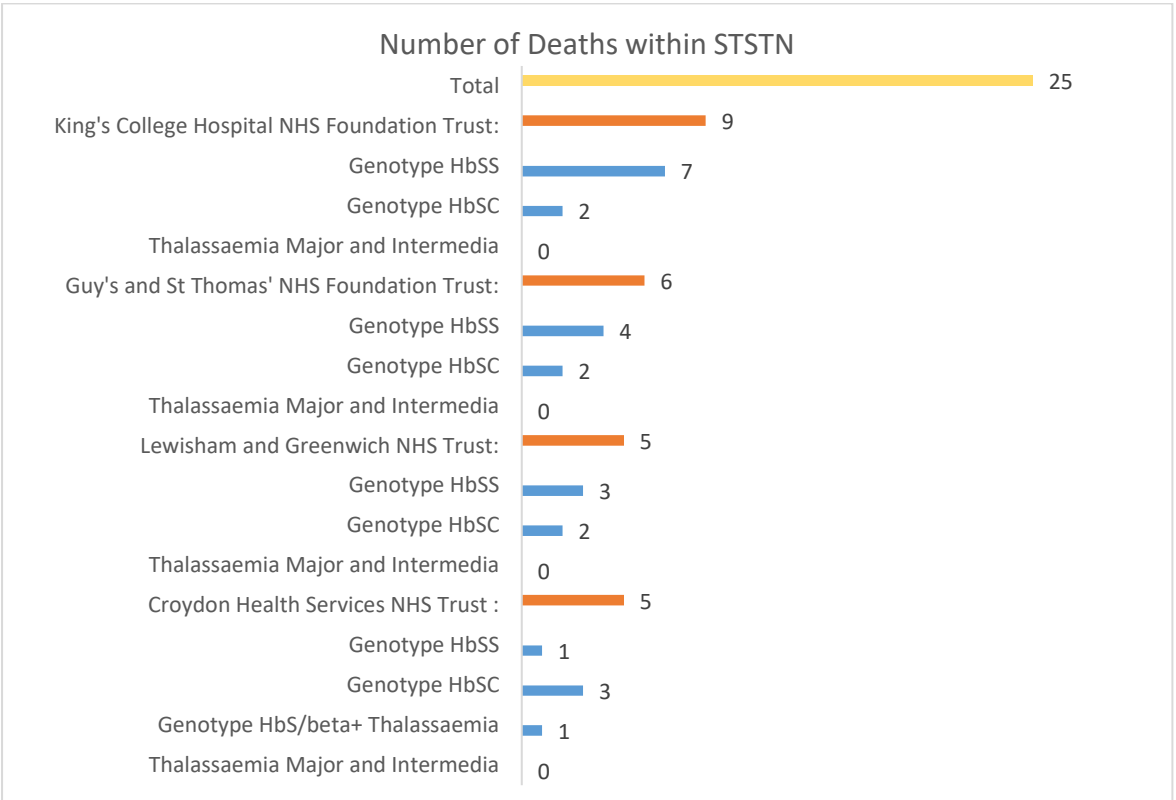
8.2 Patient activity within STSTN

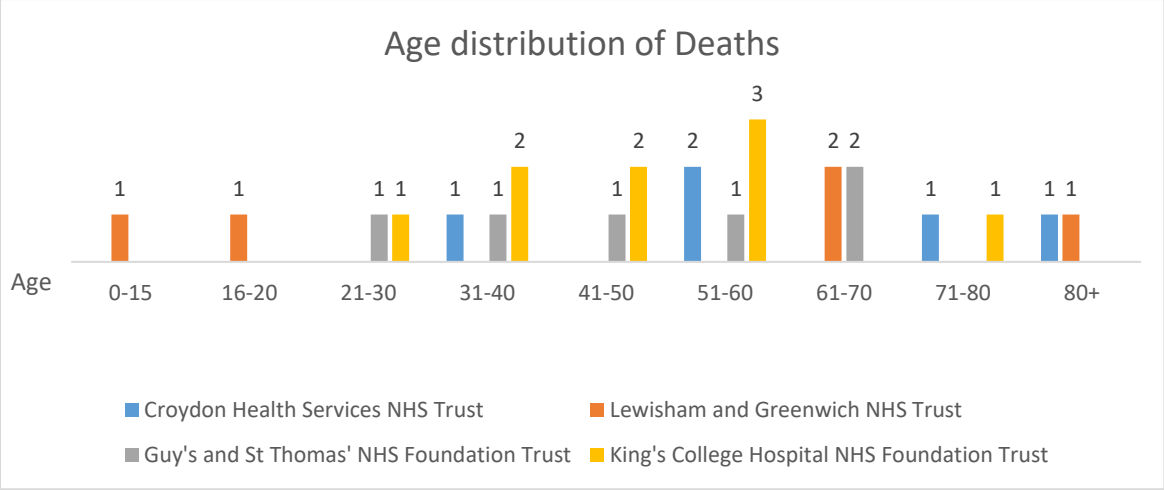


8.3 Number of pregnancies and births within STSTN

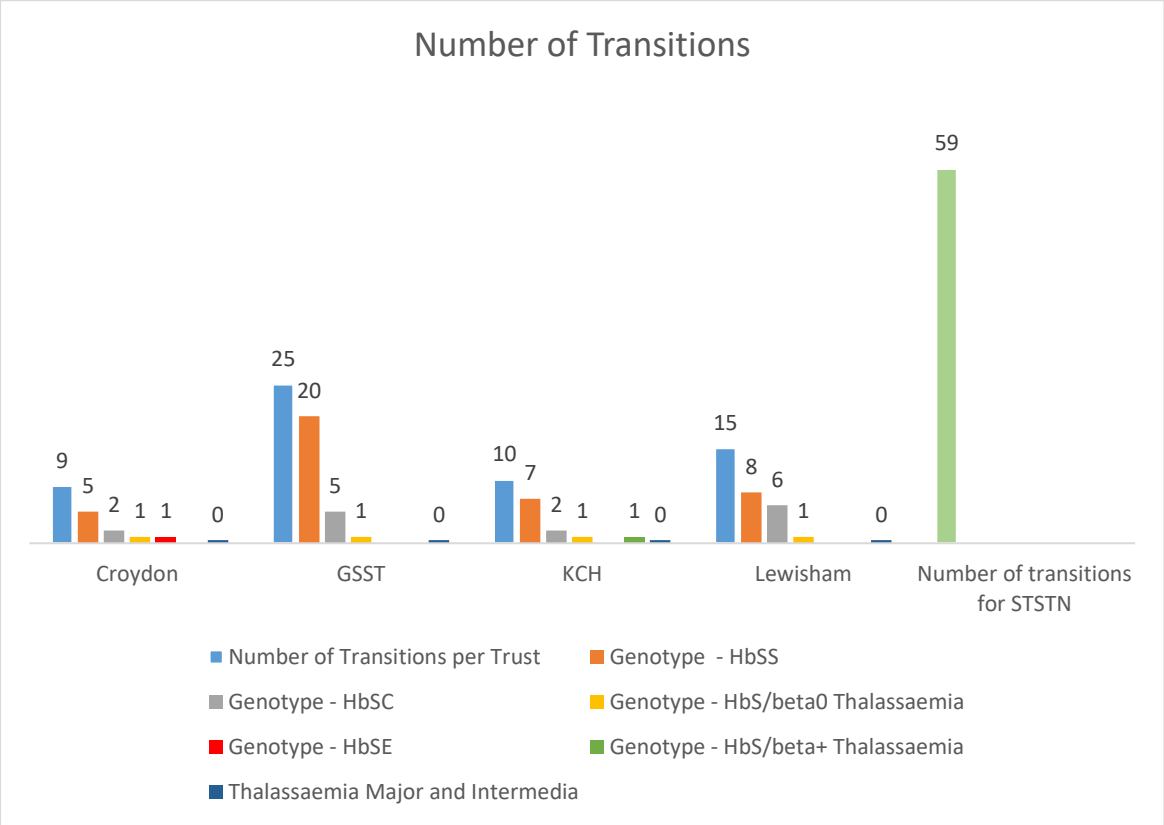


8.4 Number and age of deaths within STSTN





8.5 Number of transitions from paediatric to adult service within STSTN



8.6 Number of patients on Hydroxycarbamide within STSTN

Number of patients on Hydroxycarbamide			
	Paediatric	**Adults**	**Total**
Croydon Health Services NHS Trust	58	47	105
Guy's and St Thomas' NHS Foundation Trust	99	224	323
King's College Hospital NHS Foundation Trust	176	196	364
Lewisham and Greenwich NHS Trust	141	93	234
Total	474	552	1026

8.7 Number of STSTN patients on chronic transfusions

Number of patients on chronic transfusions			
	Paediatric	Adults	Total
Croydon Health Services NHS Trust	6	16	22
Guy's and St Thomas' NHS Foundation Trust	40	153	193
King's College Hospital NHS Foundation Trust	23	96	119
Lewisham and Greenwich NHS Trust	19	37	56
Total	88	302	390

8.8 Number of bone marrow transplants within STSTN

Number of Bone Marrow Transplants			
	Paediatric	Adults	Total
Croydon Health Services NHS Trust	1	0	1
Guy's and St Thomas' NHS Foundation Trust	1	0	1
King's College Hospital NHS Foundation Trust	0	0	0
Lewisham and Greenwich NHS Trust	0	0	0
Total	2	0	2

9. Conclusion

The Annual Report for the South Thames Sickle Cell and Thalassaemia Network summarises the breadth of the work performed across the network during 2019/20. Highlights of this report include a summary of the inpatient, outpatient and day unit work load and the use of hydroxycarbamide and blood transfusion therapy. We also include data on our births, pregnancies as well as national comparative performance data. This report also showcases our extensive educational programme which included multidisciplinary educational events, specialist registrar and nursing training and our comprehensive audit and research programme and our patient engagement work. We have achieved this through working together with our multi-disciplinary teams and our highly talented and compassionate medical, nursing and psychology teams. An overview of the work of our psychology teams is also included here.

The designation of King' College Hospital/Guy's and St Thomas' Hospital as the Haemoglobinopathy Co-ordinating Centre for South East London and South East and the designation of four of our centres as Specialist Haemoglobinopathy Teams gives further impetus to the development of services across the network. The COVID-19 pandemic has impacted on our work, as it has impacted our patients but we hope to learn lessons about new ways of working and aim to improve our virtual education output this year. We look forward to consolidating and improving haemoglobinopathy care during 2020/21 and plan to include the work of the HCC and of the local centres in our next annual report.

10. Appendix

Psychology Service for Adults with Sickle Cell & Thalassaemia, King's College Hospital.

Annual Report 2019-20

Summary

This report summarises the activity of the Psychology Service for Adults with Sickle Cell & Thalassaemia based at King's College Hospital between April 2019 and March 2020. Within this time frame the service has:

- Seen a total of 82 patients for individual psychological assessment, and of these, 43 were seen for an intervention;
- Introduced the IMPARTS screening system into haematology clinics to assess the psychosocial needs of patients attending for an annual review or who are new to the service, in order to identify the type of help they may need;
- Carried out cognitive assessments of five patients and continued to develop referral pathways for patients with neuropsychological needs;
- Arranged a further four joint sickle cell and pain clinics at which there was 100% attendance. Four patients went on to have joint follow up appointments with the team psychologist and a pain CNS;
- Reached a point at which psychology appointments will be recorded on the electronic patient booking system (PIMMS) so that a tariff and payments can be attached to these appointments;
- Delivered a variety of teaching and training events;
- Regularly attended and contributed to South Thames Sickle Cell & Thalassaemia Network meetings and events.

Background

The Psychology Service for Adults with Sickle Cell and Thalassaemia at King's was established in March 2017 and is fully integrated within the existing Haemoglobinopathies team. The design of the psychology service has been guided by an aim to normalise psychology, ensure timely access to psychological support, and be flexible and responsive to patient need. Service delivery is closely aligned to best practice as it continues to be developed by colleagues who make up The British Psychology Society's Special Interest Group for Psychologists working in Sickle cell and Thalassaemia.

Service Structure

The service is currently comprised of:

- Gary Bridges, Counselling Psychologist (0.8 wte, Band 8a)
- U'mau Otuokon, Honorary Assistant Psychologist (0.1 wte)

Current Challenges

Demand for the service continues to grow and staffing levels remain below the ratio of one full time psychologist to 300 patients, as recommended by The British Psychology Society's Special Interest Group for Psychologists working in Sickle cell and Thalassaemia. Currently at King's, there are 675 adult patients with a haemoglobinopathy registered, and the team psychologist is employed 0.8 WTE, resulting in ratio of 1:844. Ways of increasing capacity to see patients continue to be investigated and pursued, such as taking on a trainee clinical, counselling or health psychologist, but ultimately an additional psychologist is required to ensure that clinical need can be met and the remit of the service extended. An Honorary Assistant Psychologist post was created in March 2019, with a specific remit to assist with the implementation of the IMPARTS screening system in the Thursday afternoon clinic, and this role is currently filled by U'mau Otuokon.

The demand for the joint sickle cell and pain clinics is also high, with a waitlist having developed. Results of the IMPARTS screening confirm significant numbers of patients' experience pain that is a persistent problem and which causes significant disruption to their lives. The demand for this clinic indicates the need for this to be at least a bimonthly clinic with four patients attending each one.

The COVID-19 pandemic began to significantly impact upon service provision during March of 2020, with patients being instructed to engage in social shielding and face-to-face outpatient appointments stopped. The psychology service has had to adjust rapidly to new ways of working, including patient contacts primarily being shifted to being telephone based or via online virtual platforms.

IMPARTS Screening

The IMPARTS (Integrating Mental and Physical Health Research Training and Services) screening system was introduced within haematology clinics in March 2019. Patients attending for an annual review or who are new to the service (e.g. transferred from a different hospital or transitioned from the paediatric service) are invited to complete a series of questionnaires about various aspects of their psychosocial functioning. Patients are given this to complete on an iPad by an Honorary Assistant Psychologist, U'mau Otuokon, and scores immediately uploaded to EPR where they are reviewed during the patient's consultation.

Questionnaires used:

- The Patient Health Questionnaire-9 (PHQ-9)
- The Generalised Anxiety Disorder Scale (GAD-7)
- The IRT SMOKING questionnaire
- The Jenkins Sleep questionnaire (JSQ)
- The Work and Social Adjustment Scale (WSAS)
- Brief Pain inventory (BPI) for patients who answer that pain been an ongoing and significant problem in their life over the past three months
- Medication questionnaire (for patients currently prescribed Hydroxycarbamide or Exjade)

Prevalence Data in Adult Clinic
Based on completed data up until the 27th February 2020 for 201 patients, the following prevalence rates have been calculated:

Depression
52 out of 201 patients screened positive for probable Major Depression, a prevalence rate of 26% (based on a score of 10 and above out of 27 on the PHQ-9). This prevalence rate rises to 35% if an additional 19 patients are included who had milder symptoms of depression and scores between 5-9. The entire PHQ-9 is only given if patients score above a threshold on the initial two questions, which cover the core symptoms of depression (low mood and anhedonia). The overall score for those who complete the entire PHQ-9 can be elevated by symptoms that could also be attributed to the person's health condition, such as fatigue, so these severity ratings need to be interpreted with this caveat in mind.

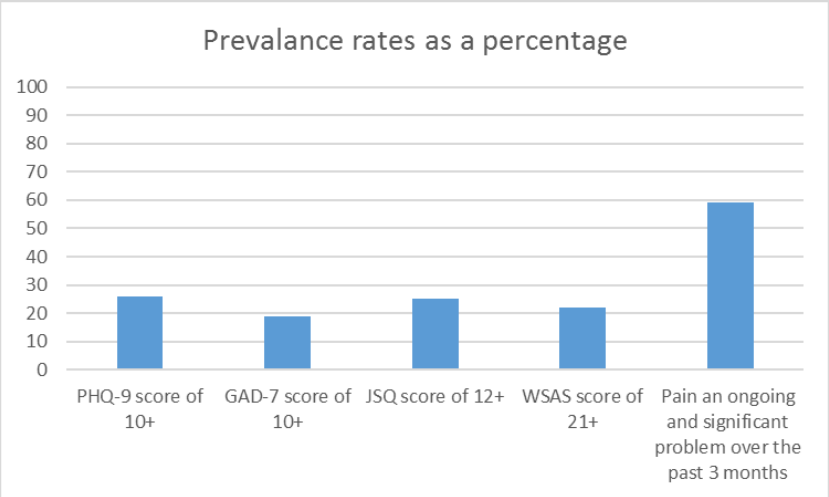
Anxiety
39 out of 201 patients screened positive for probable Generalised Anxiety Disorder, a prevalence rate of 19% (based on a score of 10 and above out of 21 on the GAD-7). This prevalence rate rises to 29% if an additional 19 patients are included who had elevated levels of anxiety and scores between 5-9.

Sleep
51 out of 201 patients had a high frequency of sleep disturbance, a prevalence rate of 25% (based on a score of 12 or more out of 20 on the JSQ). If using a lower cut off score of 5 and above, this would indicate 68% of patients had experienced poor sleep over the preceding month as compared to normal sleepers.

Work and Social Adjustment Scale
45 out of 201 patients rated the degree of impairment in their functioning due to their health condition as being in the moderately severe to severe range, a prevalence rate of 22% (based on a score of 21 or more out of 40 on the WSAS). This prevalence rate rises to 52% if those with moderate impairments are included (scores between 10-20 on the WSAS).

Pain
119 out of 201 said pain had been an ongoing and significant problem in their life over the past three months, a prevalence rate of 59%. Of these 119 patients, 52 said the pain had been in the moderate to

severe range over the past week, a prevalence rate of 44% (based on mean scores of 5 and above on the BPI Severity scales), while 60 patients reported the interference of this pain on their life had been moderate to severe over the past week, a prevalence rate of 50% (based on mean scores of 5 and above on the BPI Interference scales).



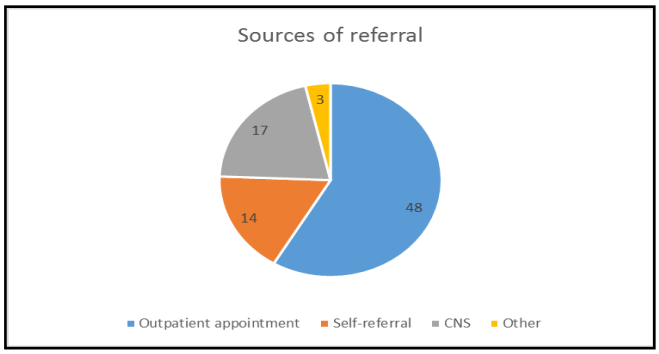
Direct Clinical Work

As this is a highly specialist service with limited capacity, there is a need to more actively seek to engage with those patients whose psychological needs are closely related to their medical condition, and calls for a specialist knowledge of sickle cell disease and thalassaemia or a multidisciplinary team approach. Decisions on which patients to focus interventions upon and prioritise are made through assessing them and through close collaboration with the rest of the haemoglobinopathies team.

Between April 2019 and March 2020 a total of 82 patients met with the team psychologist for either:

- a scheduled assessment appointment following an earlier referral, or
- an ad hoc assessment after attending a haematology outpatient appointment and being introduced to the psychologist by a member of the haemoglobinopathies team.

48 of these patients were referred by a haematologist following their attendance at an outpatient appointment, many having been identified as requiring psychology input as a result of their elevated scores on the IMPARTS Questionnaires. 17 patients were referred by the CNS team, while 3 were from other health professionals. 14 were self-referrals, of whom 9 had previously engaged in an intervention with the team psychologist and wished to have further input.

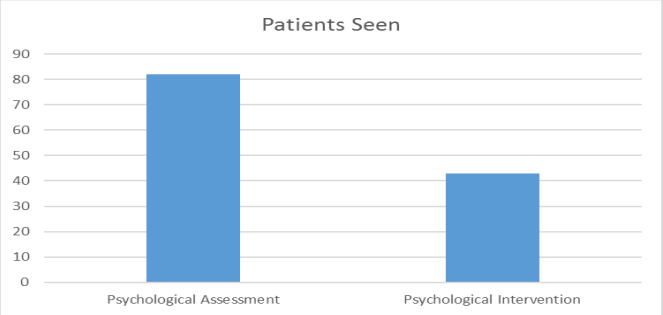


Following the assessment appointment with the psychologist, patients were either:

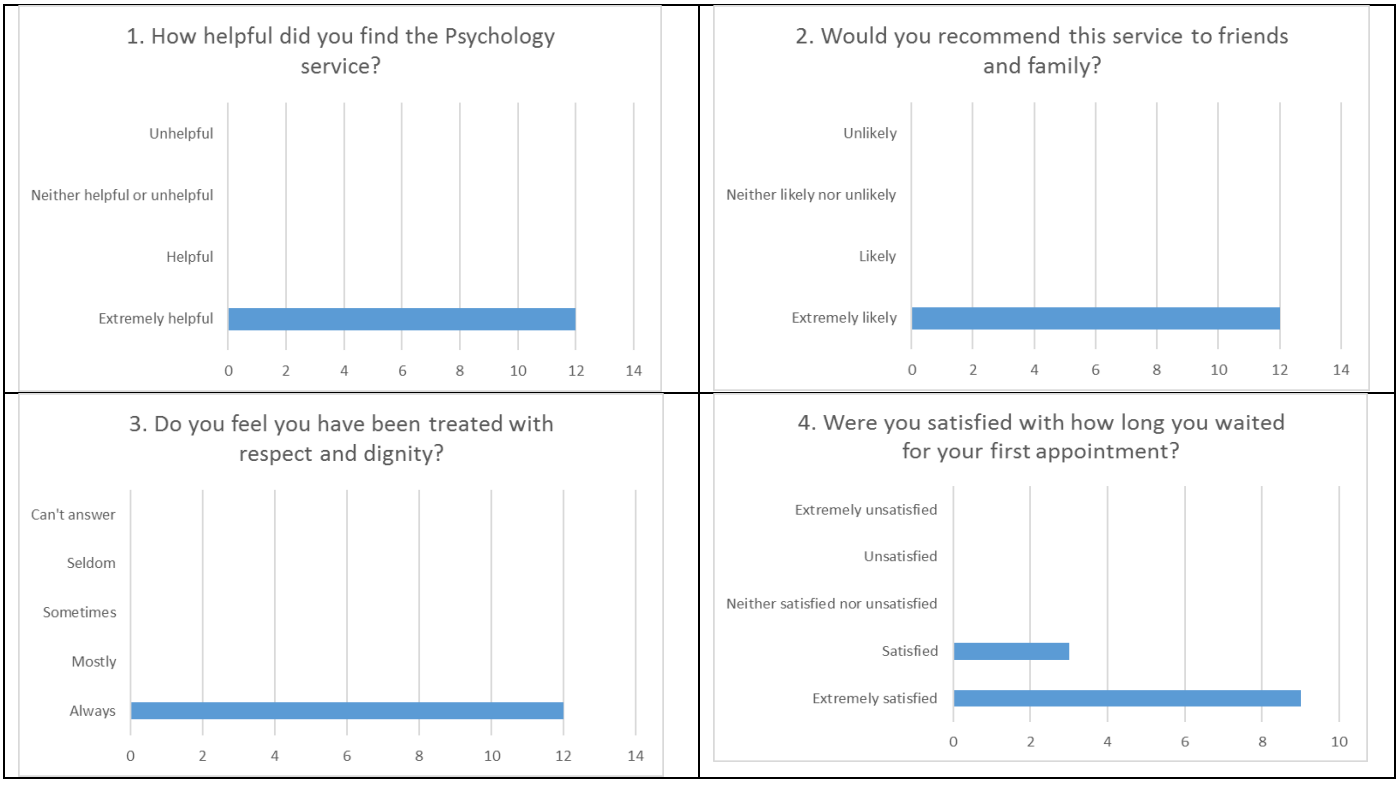
- Offered a time and date for a follow up psychology appointment for a psychological intervention.

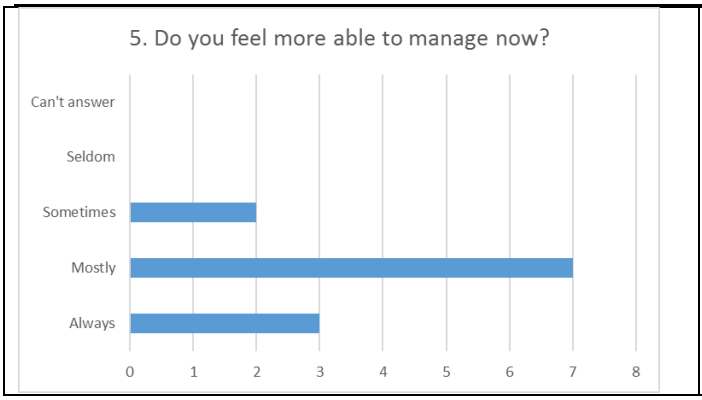
- Provided with psychoeducation and advice, and invited to contact the team psychologist if they required further support.
- Signposted or referred onto another service.

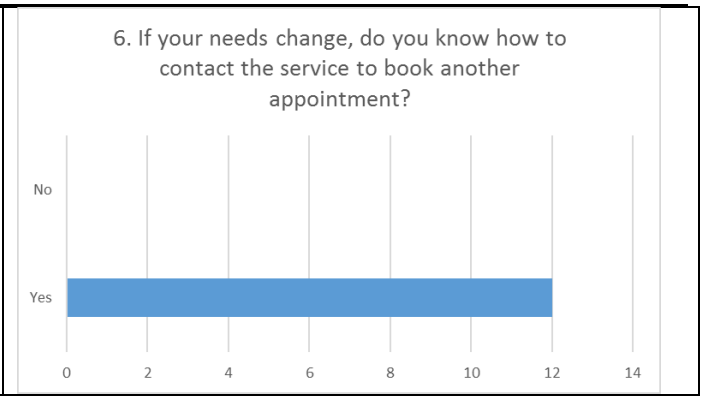
43 patients were seen for a psychological intervention. These interventions focused upon the treatment of various problem areas, including Generalised Anxiety, Depression, Post Traumatic Stress Disorder (PTSD), Functional Neurological Disorder (FND), Health Anxiety, Social Anxiety, Sleep Problems, Needle Phobia, and Interpersonal Problems. Many patients also sought help with dealing with practical problems, such as with their housing, at work/college/university, or with making PIP applications/appeals. In most cases, letters of support were provided. The development of strategies for managing pain featured strongly in a number of the interventions offered, sometimes being the main focus of treatment, while at other times secondary to other problems. Cognitive assessments were carried out with five patients using the Short Parallel Assessments of Neuropsychological Status (SPANS), and in four cases, onward referrals were made to The Wolfson Centre for Neurorehabilitation.



The number of sessions ranged from 3-20 appointments, with a mean of 7. A method for capturing anonymous patient feedback was developed using the Smart Survey website, and a link to this online survey given to patients at the agreed end of a piece of work together with the team psychologist. Return rates were unfortunately quite low, and the survey link not consistently given to patient, so there is room for improvement in this area. A summary of the responses is given below.







Multidisciplinary Clinics

The team psychologist was present or available in the following clinics:

The Haemoglobinopathies Clinics on Thursday and Friday afternoons
During these clinics, the team psychologist has seen patients for a scheduled psychology outpatient appointment or for an ad hoc assessment after a patient had attended an outpatient appointment and been introduced to them by a member of the adult haemoglobinopathies team.

The Community Clinic at The Lister Health Centre, Peckham (Weekly)
Pre-booked outpatient psychology appointments were offered on a Monday afternoon at this site.

The Transition Clinic (Monthly)
The team psychologist was present at each of these monthly clinics, and since January 2020, has been joined in representing psychology by Dr Maria Goridari, Clinical Psychologist in the Paediatric service.

The Joint Sickle Cell and Pain Clinic (Ad hoc)
The team psychologist takes the lead in organising this multidisciplinary clinic. Ten patients were seen at the three joint pain and sickle cell clinics that were held during this time period, with a 100% attendance rate for those invited. Four of these patients were followed up for appointments with the team psychologist and a clinical nurse specialist from the pain team afterwards for further interventions focused on helping them develop strategies to manage their pain and reduce the quantities of opioid-based analgesia they were taking.

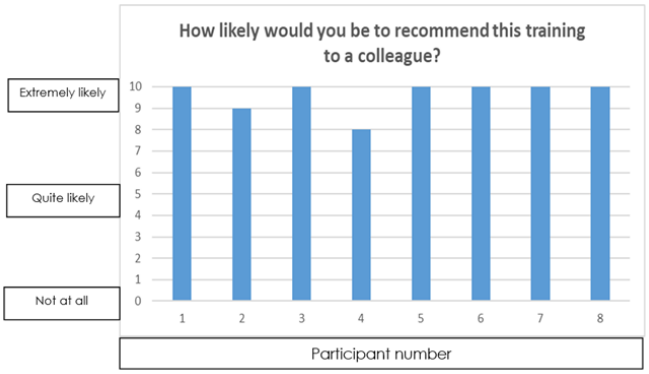
Patient Support Group

The team psychologist has attended each of the monthly patient support group meetings, and played an active role in supporting this, at times giving presentations on a variety of topics, and was also available to speak with patients individually.

Teaching and Training

The team psychologist has provided the following teaching and training:

Acceptance and Commitment Therapy (ACT) based Personal Resilience Training:
The team psychologist delivered a programme of three skills training workshops for building personal resilience and well-being during June and July 2019. The training demonstrated a range of techniques designed to enhance psychological health, personal resilience, and general life effectiveness. Twelve members of staff attended one of these workshops, ten attended two, while eight members of staff attended all three sessions. Staff included nurses form haematology wards, clinical nurse specialists, a consultant haematologist, and a matron. The eight staff members who attended all three workshops completed feedback sheets, which are summarized below:



A common theme in the additional comments made in these feedback sheets was that this training be continued and extended to other staff members.

Other Teaching:

1) The Psychological Needs of Patients with Sickle Cell Disease & Thalassaemia. Presentation delivered as part of the Introduction to Sickle Cell and Thalassaemia Study Day. King's College Hospital. 1st and 22nd Jul 2019.
2) The Amazing Teenage Brain. Presentation delivered as part of a Transition Day for patients preparing to transfer to the adults' service. King's College Hospital.16th Nov 2019.
3) Emergency Department Bitesize Teaching. King's College Hospital. 29th Nov 2019.
4) The Distressed/Anxious/Depressed Patient. Day one of the Five-day IMPARTS course 'Mental health skills for non-mental health professionals'. 4th Jun and 17th Sept 2019 and 25th Feb 2020.

Future Developments

- Develop online and virtual ways of delivering psychological interventions in light of the ongoing COVID-19 pandemic and restrictions on face-to-face patient contacts.
- Extend the IMPARTS screening system to use it as an outcome measure for psychological interventions.
- Extend the remit of the psychology service so that in addition to carrying out relatively brief cognitive assessments, more detailed assessments can be conducted with instruments such as the Wechsler Adult Intelligence Scale—Fourth Edition (WAIS-IV), and specialist supervision provided by a Consultant Neuropsychologist from King's.
- Introduce the IMPARTS screening system into the joint sickle cell and pain clinics in order to further assess psychological and behavioural responses to pain, and create workshops on developing ways of managing persistent pain for patients to attend afterwards.
- Develop and enhance the role of psychology within the transition process, in close collaboration with Maria Goridari, Clinical Psychologist in the Paediatric service, and Giselle Padmore-Payne, Roald Dahl Transition and Senior Haemoglobinopathy Clinical Nurse Specialist. Aims include the creation of psychology information leaflets for patients attending the transition clinic and the introduction of the IMPARTS screening system with a specific questionnaire to gauge the young person's readiness to transition to the adult service and take a more active role in managing their own health and healthcare.
- Develop a rolling Tree of Life programme for transition aged patients, delivered in collaboration with Maria Goridari, Clinical Psychologist in the Paediatric service.
- Continue attendance at the British Psychological Society Sickle Cell and Thalassaemia SIG, and contribute to the ongoing development of shared good practice.
- Offer placements and supervision to Trainee Clinical and/or Counselling Psychologists.
- Develop a business case for increased psychology provision within the service, linked to appointments being assigned a tariff and therefore being income generating.

The Children and Young People's Sickle Cell & Thalassaemia Clinical Psychology Service

Annual Report 2019

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 May 2019 and March 2020. Within this time frame the service:

- Between May 2019 and January 2020 the post was vacant.
- Middle January 2020, Maria Goridari, Clinical Psychologist, was appointed.
- In February and March, 12 referrals were received for individual psychological assessment and intervention.
- Regularly attended and contributed to BPS Specialist Interest Group.
- Tried to put together waiting list for neuro psychological assessment referrals, so the clinic could start running again.

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

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. The service is currently comprised of:

Maria Goridari (1.0 wte, Band 8a)

Current Challenges

- Very soon after the appointment of the new clinical psychologist, the COVID-19 pandemic broke out. Following that, the service had to adjust to new ways of working, new demands and new measures put in place.
- In person clinics and meetings were put on halt. Clinics shifted to phone clinics and meetings were reviewed for the initial period.
- Due to the above referrals slowed down. All cases referred, accepted and open had to shift to either phone or online consultation instead of in person, outpatient appointments.
- Neuro psychological assessments had to be put on halt until further guidance from regulatory and professional bodies and from Trusts and government, with regards to in person outpatient or other appointments.
- It is expected for the referrals to increase; 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. The increase in referrals was reflected in the previous report (2017). It is expected to be a challenge to balance and manage the demands, especially having one psychologist only in post.
- Current changes in the structure of the "Children & Young People's Sickle Cell & Thalassaemia Clinical Psychology Service" under the N & S CAMHS Service. Discussions are ongoing and communication is open between King's College Hospital Haematology Team and SLaM to best address these changes and the impact on the service.

Consideration is required to ensure that clinical need continues to be met and the impact of this increase on service efficiency and efficacy.

Direct Clinical Work

A total of 12 new referrals (7 Boys; 5 girls) were received by the service between February 2020 and March 2020. The age range: 5 years – 15 years.

Reasons for referral/ presenting problems;

- Pica symptoms (3 referrals)
- Enuresis (1 referral)
- Emotional regulation of anger and adjustment to health condition (1 referral)
- Procedural anxiety (needle phobia) (2 referrals)
- Generalised anxiety (2 referrals)
- Adjustment to health condition, adherence to medication and anxiety (1 referral)
- Neuro psychological Assessment (1 referral during this period)
- Anxiety possibly related to past trauma (1 referral)
- (Referrals for neuro psychological assessments started to come in the service in April 2020. Out of the time period of this report but it is important to make a brief note as it hints to the expected, upcoming increase in referrals and how that will impact on service delivery (as it had before, and it was recorded in last report produced 2017).

Location/CCG;

- Southwark, 6 cases
- Lambeth, 2 cases
- Bromley, 1 case
- Lewisham, I case
- Bexley, I case
- Hastings and Rotheram, 1 case

(Referrals for neuro psychological assessments started to come in the service in April 2020. Out of the time period of this report but it is important to make a brief note as it hints to the expected, upcoming increase in referrals and how that will impact on service delivery (as it had before, and it was recorded in last report produced 2017).

Multidisciplinary Clinics

Psychology is present or available in each clinic for:

- Sickle Cell Clinic (Weekly)
- Transfusion Clinic (Monthly)
- Transition Clinic (Monthly)
- Haemoglobinopathy MDT (Monthly)
- Combined neurology/sickle cell clinic (Bi-monthly)

Maria Goridari, also facilitates 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.

Teaching and Training

Is planned for Maria Goridari, alongside Dr Fay Coster, Clinical Psychologist at King's College Hospital for the Cystic Fibrosis and Asthma Departments, to provide the following teaching and training:

Teaching:

1) Clinical Psychology in Paediatrics, 3 hours class to 1st Year student of Doctorate in Clinical Psychology at IoPPN.

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.

- 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.

- Development and contribution to BPS SIG sub-group, with specific interest in paediatric neuropsychological screening.

- Development of psychosocial information leaflets for patients in the Transition Clinic – over 16y. Development and enhancement of the role of the psychologist in the transition clinic in close collaboration with Dr Gary Bridges, Clinical Psychologist, and Giselle Padmore-Payne, Senior Clinical Nurse Specialist and Team Lead for Adult Haemoglobinopathies, in the Adult Service, including the introduction of the IMPARTS screening system with a specific questionnaire to gauge the young person's readiness to transition to the adult service and take a more active role in managing their own health and healthcare.

- Development of rolling Tree of Life programme for patients and parents, in the future in collaboration with the Adult Service; Dr Gary Bridges, Clinical Psychologist, and Giselle Padmore-Payne, Senior Clinical Nurse Specialist and Team Lead for Adult Haemoglobinopathies.

- Thoughts about future, possible placement and supervision to Trainee Clinical Psychologists.

- Develop business case for increased psychology provision within our service.

Guy's and St Thomas'
NHS Foundation Trust

Haematology Health Psychology Service Annual Report: Sickle Cell Disease

1st April 2019 – 31st March 2020

Dr Heather Rawle, Consultant Clinical and Health Psychologist, Haematology Health Psychology Service (HPS) Lead

Guy's and St Thomas' NHS Foundation Trust

With thanks to HPS team, in particular Sekaylia Gooden and Dr Emma Sanchez-Walker, for assistance in compiling the report.

Contents

Summary

This report summarises the activity for the GSTT Haematology Health Psychology Service (HPS) for Adults with Sickle Cell & Thalassaemia between 1st April 2019 and 31st March 2020.

The report focusses on 4 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

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. 76% of referrals to the HPS are patients with sickle cell disease (SCD). The service expanded most recently in 2019 following a successful business case.

The HPS was the first in the UK to provide dedicated psychological support to people with SCD. It is mainly located within the haematology department at Guy's Hospital and is therefore well integrated within the multidisciplinary haematology teams*. It also provides some integrated care to the Centre for Haemostasis and Thrombosis at St Thomas' Hospital. We see inpatients and outpatients and offer individual evidence-based psychological therapy, group therapy/support, cognitive assessment, and joint multidisciplinary consultations. 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.

Service Structure

The HPS comprises of:

0.6 wte Consultant Clinical/Health Psychologist and Service Lead (Dr Heather Rawle – since 2001)

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)

1.0 wte Senior Assistant Psychologist (Sekaylia Gooden – since August 2019)

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).

Current Challenges and Future Developments

In March 2020, the impact of the global pandemic COVID19 became apparent for the UK. This has had profound effects on service delivery and patient experience. All patient contact was moved to virtual methods, an increase in patient and staff support has been necessary to address the additional challenges that COVID19 presents, and a rota was instigated for staff to work from home for part of the week.

COVID19 has presented the HPS with an opportunity to re-evaluate how services are delivered in order to ensure continued accessibility, particularly for those patients who are most vulnerable. Virtual appointments have greatly reduced DNA rates and virtual support group has resulted in increased attendance. We are surveying patients' preferences regarding modes of contact with psychology and therapy delivery and are searching for IT solutions so that group webinars and improved virtual support groups can be offered. We are exploring how annual review/therapy measures can be completed virtually. However it is important that face-to-face contact can be resumed for patients whereby this is clinically indicated (e.g. new appointments, trauma work, cognitive assessments) or preferred by patients. It is also important to maintain the visibility and accessibility of the HPS (for staff and patients) despite the necessity of part remote working for all staff members and this has so far been achieved by ensuring attendance at the more frequent virtual team meetings.

An additional ongoing challenge is office and therapy space – this limits patient appointments and capacity to take on Doctorate trainees and students.

Objective 1: Specialist psychological support for patients and significant others

Referrals

Patients may be seen by psychologists as required during multidisciplinary sickle cell clinic, ward round, whilst in Day Unit; for a planned course of 1:1 therapy; and in sickle cell support and therapy groups. For the time period of the report, 312 patients with SCD were referred to the HPS which represents 76% of all referrals to HPS. This is a 29% increase from the previous year's figure of 222 (73% of total referrals). This increase is likely to be due to the increased psychology resource which enabled increased psychology involvement on ward round and clinics, and also the increasing success of the support and therapy groups.

202 (65%) people were referred as outpatients (some of whom were from the haematology day unit), and 68 (22 %) were referred as inpatients. 42 (13 %) people referred themselves to the HPS.

269 (86%) people were referred for therapy, 11 (4%) people were referred for neuropsychological assessment and 32 (10%) were referred for group support (including the support group).

301 (96%) referrals were from GSTT, 11 (4%) referrals were from other hospitals such as Lewisham and QE Woolwich.

Presenting problems typically include: coping with pain and complications of SCD, difficulties making treatment decisions, concerns around adherence, health anxiety, depression, stress exacerbating health conditions, relationship problems exacerbating management of health conditions, difficulties managing studies, employment concerns, self-esteem problems, needle phobia, lifestyle management, and drug and alcohol issues that exacerbate management of health conditions and memory problems. Some patients have additional major health problems that may or may not be directly related to their SCD, e.g. end stage renal disease, visual loss, and stroke, and of course this amplifies the psychological burden of their conditions.

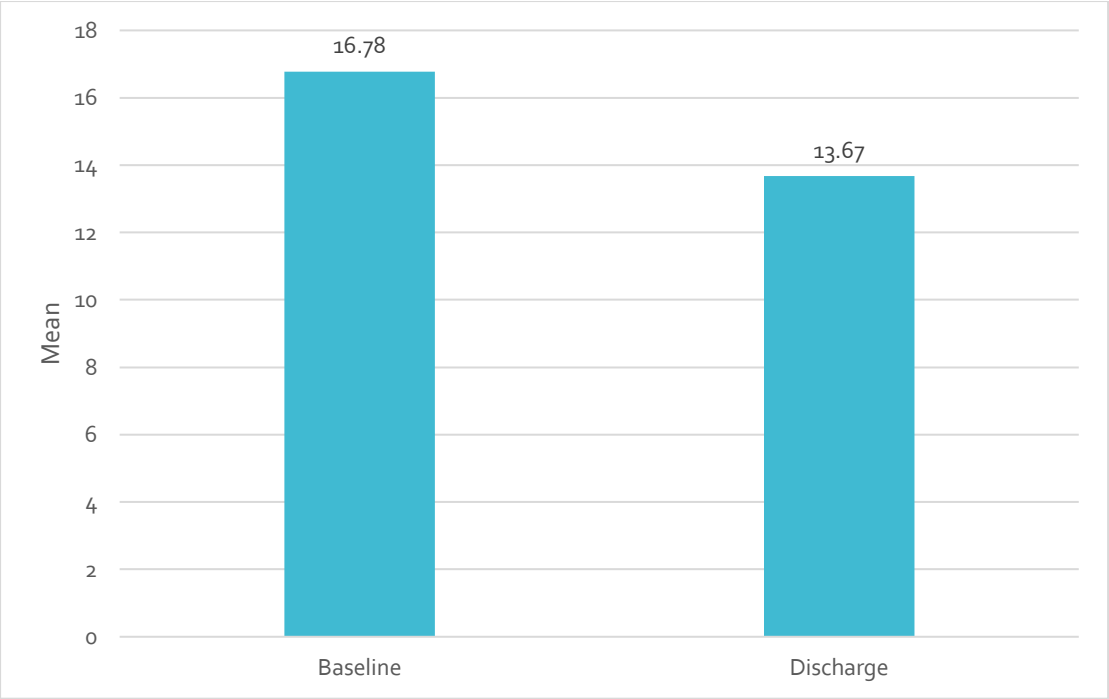
Outcome data

All patients are offered psychological support according to their presenting problems and preferences and those who receive one to one support complete pre-, mid- and post- treatment measures in order for their progress to be assessed and recorded. Over the time period of the report last 12 months, 39 patients [12 (31%) males and 27 (69%) females; age range from 18 to 77 years old] have completed baseline mood measures prior to engaging in subsequent 1:1 therapy sessions.

The results below (Figure 1) are based on a subset of patients who had complete information on baseline and discharge outcome measures (30).

	Baseline score	Discharge score
GHQ-28*	16.78 (6.32 SD)	13.67 (5.79 SD)

Figure 1: Bar chart displaying the mean GHQ-28 scores at baseline and discharge



*The *General Health Questionnaire (GHQ-28)* is a self-report measure which is used to detect emotional distress related to general medical illness. It measures four domains which include somatic symptoms, anxiety and insomnia, social dysfunction and severe depression. The severe depression domain includes two risk questions which investigates suicidal ideation. The GHQ is scored using the chronic conditions methods. It is generally believed that a score between 0-4 indicates no distress, 4-10 indicates an abnormal level of distress and between 10 and 28 indicates severely abnormal distress.

As can be seen, patients have high mean levels of distress at baseline and these are reduced at discharge. Statistical analyses (paired t-tests) reveal a significant difference between patients' baseline and discharge GHQ-28 scores, (p= 0.01). Statistical measures of patients GHQ-28 scores at baseline and mid-treatment were found to be significant (p<*.001).*

Previous service data and research show psychological support is associated with reductions in distress, improvements in coping, improvements in confidence and self-esteem, and reductions in length and frequency of hospital stays (Thomas et al, 1999, 2000, 2001).

The main interventions delivered by the HPS include:

- ACT (Acceptance and Commitment Therapy) – which is a third-wave Cognitive Behavioural Therapy (CBT) aiming to support the person to develop greater psychological flexibility. It involves a particular emphasis on mindfulness and values-directed actions
- Narrative therapy, Cognitive Analytic Therapy
- Motivational Interviewing, Solution-focussed therapy – brief therapy focussed on solutions rather than exploring problems

Annual Review and New Patients to Sickle Cell Disease Clinic

Once a year all patients with SCD are seen in SCD clinic for an annual review by SCD team and this includes a review by the psychologists. The purpose of this review is to:

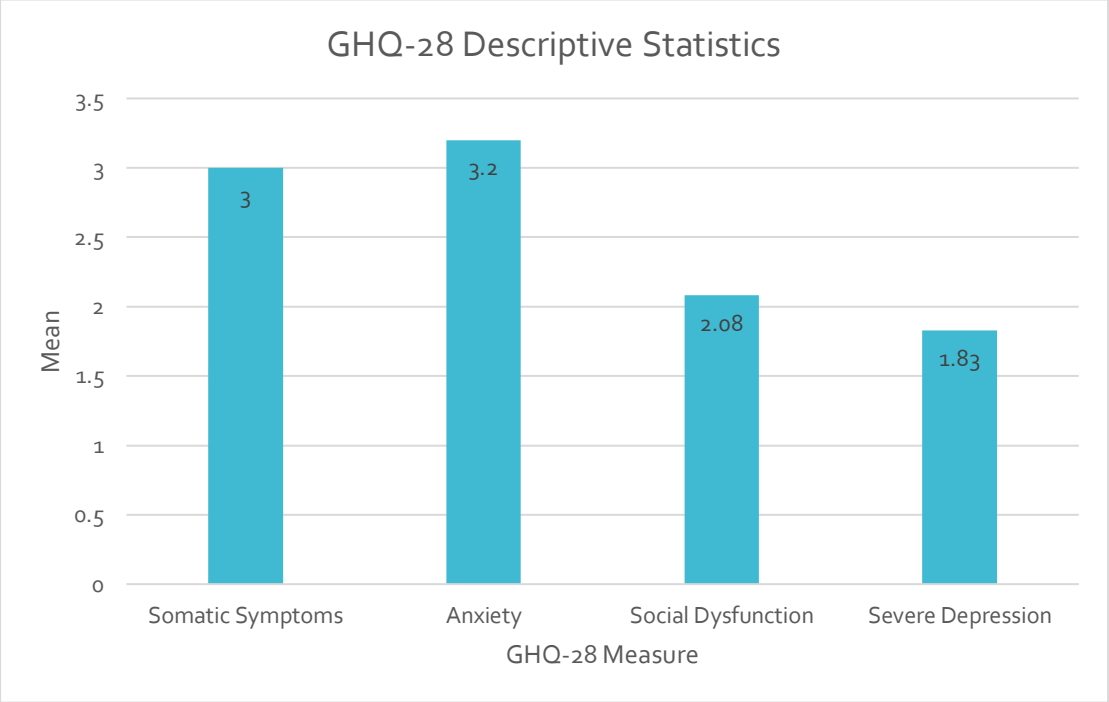
1) Assess patients' coping with their condition, confidence in managing pain, mood, and quality of life (using formal measures and face-to-face interview)

2) To normalise the role of psychology in the MDT and to inform patients about the HPS and how to access it.

For the time period of this report, we collected data from 67 patients who attended SCD clinic and who were identified as 'new' to clinic or 'annual review'. Patients who completed psychological measures included 38 females (56.72 %) and 29 (43.28 %) males with their age ranging from 17 to 68 years. We did not keep a record of numbers of patients seen in SCD clinic who declined to complete measures.

GHQ-28

Figure 2: Bar chart demonstrating the distribution of scores across the sub sections of the GHQ-28



The GHQ-28 scores below are from 59 SCD patients with complete data assessed within the last 12 months (Figure 2). Table 1 shows that the sickle cell patients attending clinic on average show a significant level of distress. However, as can be seen from the range a wide difference occurs in the total scores obtained by patients.

Table 1 – GHQ-28 descriptive statistics

General Health Questionnaire	Mean	Standard Deviation	Minimum	Maximum
Somatic symptoms score	3.00	2.21	0	**7**

Anxiety and insomnia score	3.20	2.33	0	**7**
Social dysfunction score	2.08	1.69	0	**7**
Severe depression score	1.83	2.47	0	**7**
Total score	**10.11**	**8.70**	**0**	**28**

Quality of Life: WHOQOL-BREF

The World Health Organisation Quality of Life Scale Brief Form (WHOQOL – BREF) is a self-report questionnaire in which patients are asked to rate the quality of different aspects of their life. The questionnaire measures four domains which include physical health, psychological health, social relationships and environment. The scores below are from 20 SCD patients assessed in SCD clinic within the last 12 months. As can be seen from Table 2, patient mean scores are lower than the population norms, indicating that patients with SCD rate themselves as having a lower QoL compared with population norms.

Table 2 - WHOQOL-BREF descriptive statistics

WHOQOL_BREF	Mean	Standard Deviation	Minimum	Maximum	Preliminary Population Norms*
Physical health	73.03	28.65	21.42	160.71	**73.5**
Psychological health	66.66	27.64	4.17	100.00	**70.6**
Social relationships	66.23	26.00	16.66	100.00	**71.5**
Environment	71.41	13.08	46.87	100.00	**75.1**
Total score	**277.33**	**95.37**	**101.34**	**460.71**	**--**

Pain Self-efficacy: PSEQ

The PSEQ is used to measure both the strength and generality of a patient's beliefs about their ability to accomplish a range of activities despite pain. 25 patients with SCD completed this measure in the last 12 months and scored a mean total score of 34.80 (SD 17.96). Scores ranged from 3 to 60 (maximum possible score). The higher the score, the greater the belief of self-efficacy indicated. The results suggest a wide variability in our patients' level of confidence in coping with their pain.

Illness Perceptions: Brief-IPQ

The Brief Illness Perception Questionnaire (Brief-IPQ) measures the cognitive and emotional representations of illness and comprises five items on cognitive representation of illness perception which includes consequences, timeline, personal control, treatment control, and identity. 15 SCD patients have been assessed in the last 12 months and scored a mean total score of 46.13 (SD 21.16).

Scores ranged from 11 to 110 (maximum score is 110). A higher score is reflective of a more threatening perception of the illness.

The questionnaire also incorporated two qualitative questions which ask patients to list in rank order the most important factors which caused their sickle cell disease and which cause their sickle cell crises.

The majority of patients (11 out of 15) named genetics or parents/ hereditary as causing SC disease. Other responses included luck/chance, and lack of parental awareness/ knowledge/education.

The following responses were recorded as common causes of SC crises, which are ordered by the frequency that they were mentioned (most frequently mentioned at the top): Cold weather, Stress, Diet, Exercise, Infection, Sleep/Tiredness, Dehydration, Infection and Drinking Alcohol.

This suggests that the majority of the patients sampled had an accurate understanding of causes of their SCD crises.

Work and Social Adjustment Scale (W&SAS)

The Work and Social Adjustment Scale* was completed by 18 patients with SCD within the last 12 months. The W&SAS aims to investigate how a patient's condition impacts on their day to day activities. Scores below 10 (as indicated by the total mean score) are believed to indicate subclinical populations, scores between 10 and 20, are associated with significant functional impairment and scores over 20 indicate moderately severe pathology. As shown by Table 3, the sickle cell patients sampled indicated significant impairment on their day to day activities although there is wide variability in this.

Table 3. Descriptive W&SAS statistics

W&SAS	Mean	Standard Deviation	Minimum	Maximum
Work	2.50	3.08	0	**8**
Home Management	1.83	2.29	0	**7**
Social leisure activities	2.44	2.81	0	**8**
Private leisure activities	1.72	2.21	0	**7**
Family and Relationships	2.39	2.91	0	**8**
Total	**10.88**	**13.30**	**0**	**38**

*Mundt, J. C., I. M. Marks, et al. (2002). "The Work and Social Adjustment Scale: A simple measure of impairment in functioning." Br. J. Psychiatry 180: 461-4.

SCD Weekly Ward Rounds & Inpatient Activity

The psychology team attends the Monday morning multidisciplinary haematology patients' handover meetings and Monday sickle cell Consultant-led ward rounds. In addition we continue to provide focussed bedside counselling to inpatients as required. From March 2020, inpatient contact has been via phone due to COVID19 and full MDT ward rounds in person have not been permitted. Contributing to MDT ward round enables the psychologists to support the SCD team and the ward

staff in thinking holistically about patient care, provides opportunities for informal support and debrief of staff.

SCD Specialist Therapeutic Groups

Raselle Miller and students facilitated 2 therapeutic groups called the 'Tree of Life' Group which is based on narrative therapy principles and is a tool for sharing stories about roles, identities, values and strengths. The completed trees were presented in the haematology reception area and others (patients and staff) were invited to comment on content.

Participants were invited to comment on:

What they enjoyed about the group: "Meeting up with sickle cell patients and learning about their stories. Encouragement of us all during our time together". "I enjoyed the openness of our discussions. I enjoyed the interaction with the health psychologists". "I enjoyed being with others that have the same illness as me and knowing that we all feel the same".

What they would take away from the group: "I am much more than sickle cell and much more of a person than I realise. To take on the positives of what I have learned about me and others. The hard work that the psychologists have put into this group and for giving us a voice 10/10"; "More confident, looking forward to a good future".

What could be improved: "Create more awareness so more people can sign up to participate. If possible sort out transportation because most people really want to attend but probably thinking of the cost of extra transportation to get home".

Further groups that were planned in March 2020 were postponed due to COVID 19.

SCD Psychology Support Group

The HPS continues to offer a weekly out of hours support group for patients with SCD. These groups are psychology led and sometimes co-facilitated by a patient representative. They are offered on a continuous basis and where possible are covered by other clinicians to prevent breaks due to annual leave. For the time period of the report there were 41 groups, including the Christmas Party in December 2019 and an Employment Talk in January 2020 (Figure 3). Two groups were cancelled in March 2020 due to the outbreak of Covid-19 and subsequent shielding of SCD patients. The service adapted to this by providing the support group in a virtual format from April 2020.

On average, there were two attendees per session. The fewest number of attendees was zero (no attendance) and the largest group was five. The exception to this was the Employment Talk in January 2020 where 21 people attended. This talk was run by Professor Simon Dyson and received positive feedback.

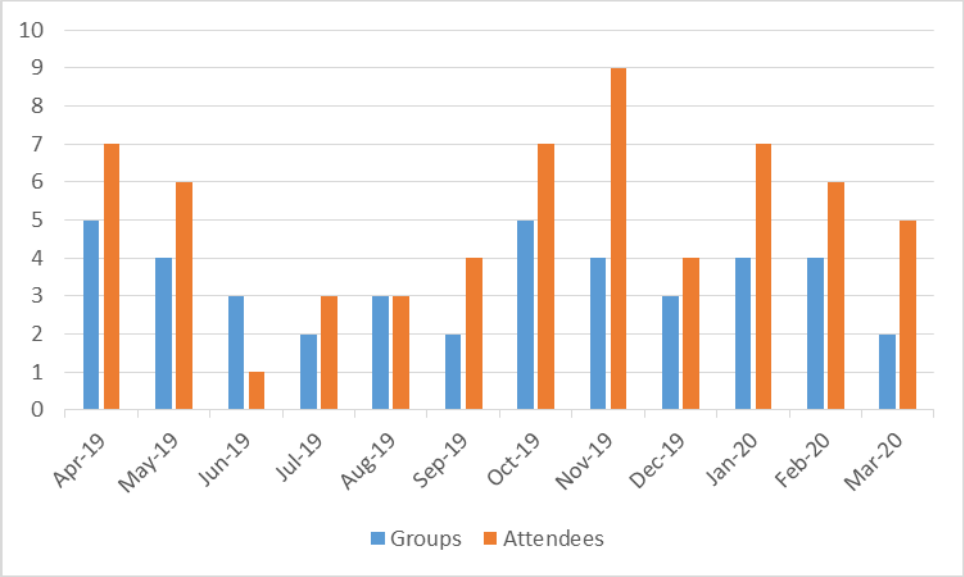


Figure 3: Bar graph showing number of attendees at Support Group across the year, including number of groups and number of attendees. Note: January 2020 also had 21 attendees at the Employment Talk which have not been included to prevent the data being skewed.

The main themes from SCD support groups during this year:

- Reflections on ward and haematology day unit experiences
- Bereavement support
- Stigma around SCD diagnosis
- Chronic and acute pain management
- Managing external / internal triggers to SCD crisis
- Impact of recurrent SCD crisis on relationships and family life, including SCD within their family, e.g. how to be parent with SCD and experience of being parents having SCD
- Making decisions about medication and treatments, including perceived benefits and costs
- Communicating effectively with health care professionals
- Impact on employment, including managing SCD crises in work, stress management in context of work and disclosing SCD diagnosis to employers
- Adjusting to lifespan stage changes, e.g. living on own, children leaving home.
- Reproduction with a sickle cell diagnosis
- Self-care, and life style management whilst living with SCD
- Use of social support and networking with peers as a coping strategy for SCD management
- Coping with recurrent hospital admissions; challenges to recovery when in hospital; barriers to effective care in hospital.
- Psychological impact of SCD (including depression, anxiety, anger and sleep difficulties)
- Coping with housing and welfare support issues, including immigration and PIP applications

'My Sickle and I' Event - **co-hosted by the Sickle Cell Society and GSTT sickle cell team** (sponsored by Cyclerion)

On 29th February 2020, a group of 28 men of different ages and backgrounds from across the country met in London to discuss their experiences of living with Sickle Cell.

The group discussion was co-facilitated by RM and ESW from our psychology service, and offered a space to start a conversation about what it is to grow up and live with Sickle Cell purely from a male perspective. We believe this was the first all-male group of this size in the UK.

People were courageous in sharing their stories and experiences, with people finding similarities and differences in relation to how Sickle Cell had influenced their lives. There were a range of topics discussed including disclosing to others, employment, family life/relationships and health experiences, such as pain, priapism and mental wellbeing.

The feedback from the event was very positive, including many saying that the event was the largest group of men with sickle cell they had met. All respondents of the anonymous survey said they were more likely to involve family/friends in their SCD journey as a result of the event's conversations. They were also more likely to share more/be more open, both with others that have Sickle Cell and with those who do not know about it. Many of the attendees hope for it to become a regular event.

A recording of highlights of the event can be found at:
https://scanmail.trustwave.com/?c=8248&d=59_e3txmGUNF_rCIGDL5g6fXl6VaIR01AIdVjES3Mg&u=https%3a%2f%2fwww%2eyoutube%2ecom%2fwatch%3fv%3dYK6Eabey70A

Joint SCD/Neurology Clinic

This monthly multidisciplinary clinic is jointly held by the neurologist and adult sickle cell team. The psychologist's role in the clinic is to identify patients who require neuropsychological testing, to examine the effect of stroke and other neurological events on mood and coping, and to contribute to the team's understanding of patients' presenting difficulties. Many patients are already known to the psychology team so a contribution can be made to the team's understanding of the patient regarding neuropsychological functioning or mood and coping issues. Patients not already known to psychology are offered a brief mood and coping assessment and considered for neuropsychological assessment. Some of the patients were seen 1-1 during/after clinic for psychological assessment/support relating to issues arising during the joint clinic consultation.

SCD Cognitive Assessments

For the time period of the report, 11 patients with SCD were referred for cognitive assessment and these were added to the existing waiting list. All patients on the neuropsychology assessment waiting list were contacted via letter to explain they would be offered an appointment as capacity allowed and to make sure they contact their referrer or GP in the meantime if they had further concerns. Lengthy waiting lists for neuropsychology assessment are common in other psychological services but the HPS aims to minimise this wait which can only be achieved by securing further psychology resource (as per aims of business case). In March 2020, all cognitive assessments were postponed until further notice due to COVID19 as it was not deemed appropriate to conduct these virtually.

Sickle Cell Adolescent Transition

This multidisciplinary transition clinic is run jointly between the paediatric and adult sickle cell team on every month (during summer/school holidays it's a longer gap in between clinics) with the objective of preparing adolescents for the transition from paediatric to adult care. The psychology team contributes to this clinic by offering assessments to adolescents where necessary, and an explanation of the adult HPS is provided. All adolescents who are transferred to the adult service are routinely seen by the psychologists for baseline psychological and quality of life assessments.

The psychologists also contribute to the facilitation of transition workshops, with the aim of focussing on exploring parent's and patients' concerns about transfer to adult services and also normalising the role of psychology in the adult SCD team.

Sickle Cell Outreach clinic

This multidisciplinary outreach clinic is run jointly between SCD GSTT team and adult sickle cell team in Brighton, Medway and Southampton Hospitals every 3 months. The psychologists' role in the multidisciplinary outreach clinic is to undertake brief assessment of depression/anxiety and ways of coping with their health condition, and to introduce the psychological support available to patients by their hospitals or via GP where appropriate to patients who are not aware of support available. Within the context of sickle cell, undertaking routine screening of depression is particularly important because living with a chronic long term condition is known to affect mood.

In the last 12 months, the psychologists attended two of these clinics and carried out review of 7 of the patients who attended clinic. Patients seen were aged between 18 and 71 years old. Three of the patients were referred to their GP for more local psychology support around their mood management and patients are encouraged to contact the HPS by phone.

Patient Experience

The HPS continues to be involved in efforts to improve patient experience and works closely with patient representatives who have sickle cell disease by involving them in support groups, staff training, and service consultations.

Patients' Evaluation of HPS

A sample of patients attending HPS were asked to complete a survey to find out more about their experience of using the service and suggestions for improvements. 12 were completed.

Summary of quantitative statistics from HPS evaluation form:

People were asked to rate the following statements from 0 (extremely unhelpful/ unsupportive/ unsatisfied/ uncomfortable) to 10 (extremely helpful/ supportive / satisfied/ comfortable)

Question	**Mean**	**N**
How helpful has the psychological support been in assisting you in coping with your problem(s)?	9.45	11
How would you rate the psychologist's ability to provide emotional support?	9.58	12
How satisfied were you with the waiting time to be seen for psychological support from the service?	8.42 (including one outlier of 1/10)	12
How satisfied were you with the room that the psychologist saw you in?	8 (including one outlier of 3/10)	12

Summary of qualitative data from HPS evaluation form:

Everyone who completed the questionnaire said they would recommend the service to others. We also asked for feedback on preference for face to face compared to telephone sessions: nine people preferred face to face, one person preferred telephone and one person preferred a mixture of both. The reasons for people not being able to make appointments were that they were too tired, unwell, had too many appointments, distance to travel or that they forgot. Only one person answered the question about the least helpful aspect of the psychology service, which they said they found it difficult to tell the "whole truth" about how they felt.

People mentioned the following themes in response to questions about the service:

What were you hoping to gain from psychology sessions? (N=12)
• Support and help understanding some of my fears and frustrations/concerns • To have a better understanding of myself and my reaction to life events. • Acceptance of illness/condition and guidance in how to cope with it, e.g. support networks, self-care • Help with mood – e.g. peace of mind, control worrying • Coping with needle phobia • Someone to listen and bring other thoughts

What was the most helpful aspect of the psychology service? (N=12)
• Feeling really understood by therapist and gaining understanding about what to work on • Relating seemingly distant elements and seeing how they form the picture • Psychologist being friendly, empathetic and trustworthy. • Having someone to talk to and listen who is not emotionally involved, that can then give you useful advice and ways to cope • Being given specific advice and/or skills by a psychologist to deal with certain issues • Being able to vocalise my thought processes. • Learn more about the needle phobia (why does it happen) and find ways to reduce the anxiety and not faint (applied tension) • Being able to be open and honest

How could the service be improved? (N=8)
• Nothing to be improved (6 answers) • Only that it should be available at the time of diagnosis to help people process thoughts and information • Maybe facilitate some 'real life' exposure

Objective 2: Staff support, training and consultation

Individual support: Staff approach members of the psychology team on an individual basis for support relating to their experience of caring for haematology patients – this may be planned or unplanned. From March 2020, staff have also sought support regarding the impact of COVID19.

Group support: Regular reflective practice/support sessions and one-off debriefs as required are facilitated by the HPS

- Esther Ward nurses (monthly)
- Samaritan Ward nurses (monthly)
- Haematology Day Unit nurses (bi-monthly)
- SCD clinical nurse specialists (monthly)
- Junior doctors (weekly – this is a pilot group conducted in conjunction with Psycho-oncology Support Team)

Reflective practice/support sessions are evaluated. Most attendees rated the sessions as 3 or above (whereby 1 = not at all, 5 = definitely) on Process (e.g.it was a safe space to reflect; I was treated with respect); Content (e.g. difficult conversations with patients); and Confidence (e.g. ability to work with patients with haematology diagnoses; communicating questions, concerns and experiences). Written comments included: 'the mindfulness exercises are so beneficial – I feel it sets you up for the day ahead'; ' I felt it was a relaxing, non-judgemental, great opportunity to share experiences and challenges that may have been stressful'; 'love this session'.

Ward Nurse Away Days

RM and HY contributed to the Esther Ward and Samaritan Ward Away Days Sickle cell disease teaching alongside CNS colleagues. Discussions included a nursing perspective of delivering care to SCD patients and the psychological impact of sickle cell.

Nurse Teaching

The HPS contributed to the rolling SCD team teaching programme for GSTT ward nurses and midwives presenting on 'Psychological issues in sickle cell' 'Pregnancy and SCD: psychological considerations and care' and 'The role of health psychology in SCD team' alongside expert patients.

SCD Team reflection meeting

In February 2020, the psychology team facilitated a SCD team event using the Tree of Life as a tool for sharing stories about roles, identities, values and strengths. This was attended by the whole SCD team including consultants, advanced nurse practitioners, clinical nurse specialists, community nurse, and medical secretary. Feedback suggested the meeting had been helpful:

All participants rated attendance of the event as "good" (2) "very good" (4) or "excellent" (4).
All participants felt at least "somewhat" safe to express themselves and listened to when they shared their experiences.

Quotes:
"I think it was a great exercise and an opportunity to learn more about the team I work in!"
"Thought the session was really well facilitated and planned"
"The whole day was very useful for team bonding and awareness. It was very well facilitated. The discussion of challenging patients was very helpful. It would be good to do more frequently as we didn't have a lot of time"

Suggestions for improvement: To have more time to learn and share, and to invite wider members of the MDT.

Objective 3: Promotion and improvement of psychological aspects of haematology services at a local and national level

Post-graduate Psychology Programmes

The psychologists lecture on the Doctorate in Clinical Psychology training programme at the Institute of Psychiatry, Psychology and Neuroscience and the King's College London MSc Health Psychology course (Module: Assessment and Health Psychology in Practice). The focus of the sessions are on the psychological and neuropsychological aspects of sickle cell disease, culture and diversity in psychology, and the development of a health psychology service to meet needs.

Feedback included: "It was good to have an overview of sickle cell disease. I found the case studies the most interesting and helpful part of the teaching as it really bought the content to life. It was really interesting to hear about how the psychology team in the service had changed over time and to think about what being part of the team really means"; "Fantastic session. The slides are an amazing resource for all things SCD. I loved the case studies and discussions around psychological aspects. Really useful!"

Supervision of, and Consultation to, Psychologists Outside GSTT

HR provides supervision to: Gary Bridges (Counselling Psychologist in Sickle Cell Disease), Kings College Hospital (Income generating activity)

HR provides consultation to psychologists new to roles in SCD and advising re business cases.

Influencing Local and National Policy

HR is a member of the Peer Review Haemoglobin Disorders Steering Group and the Haematology Institute Red Cell Working Group, and attends meetings held by South Thames Sickle Cell and Thalassaemia Network, NHS London Haemoglobinopathies Group, and King's Health Partners Haematology Institute Elimination of Leukaemia Fund Mind and Body Working Group. Such representation helps to ensure that psychological needs of patients are on the agenda and that services are developed and commissioned with psychology in mind. Representation of UK psychologists working in Haemoglobinopathies is aided by our development and chairing of the British Psychological Society Special Interest Group for Psychologists working in Sickle Cell and Thalassaemia.

British Psychological Society Special Interest Group for Psychologists working in Sickle Cell and Thalassaemia

The HPS team has initiated, facilitated and host special interest group meetings of psychologists who work with people with SCD from across the UK. The HPS team formalised the group in 2010 to become a British Psychological Society Special Interest Group (SIG). The group is a forum for sharing best psychological practice and enables joint key contributions to national documents such as SCD Standards. This group is usually hosted in the GSTT haematology department by the GSTT SCD health psychology team and has an active email forum. Meetings were held five times during the time period of the report and were moved to monthly virtual meetings from March 2020 due to COVID19. The SIG is attended by psychologists working in London as well as outside coming from Nottingham, Manchester, Leicester and Ireland and the benefit of virtual meetings was that they could be accessed by more psychologists.

Conference Presentations

June 2019: Haematology Psychology Service - Standing the Test of Time (HR, RM, Nicky Thomas, Latte Iddi (service user)) KHP Psychology Conference, London

July 2019: Tree of Life (HR) STSTN Sickle Cell Awareness Day, London

October 2019: Tree of Life (RM) Annual Academy For Sickle Cell and Thalassaemia Conference (ASCAT), London

December 2019: Haematology Health Psychology Service and Tree of Life (HR) KHP Haematology Nursing and Allied Health Professionals Conference, London

Objective 4: Specialist trainee and student placements

The HPS continues to attract a continuous stream of students/trainees. MSc and self-directed placements are for 3 days per week for minimum 3 months. For the period covered by the report, the HPS attracted six students/trainees:

- MSc Health Psychology (KCL, Middlesex): Mira Zuchowski; Nana Arhin; Flavia Birikorang
- Undergraduate one year placement: Tariq Wright; Angharad Townsend-Smith; Isaac Sanderson;

Governance

Continuous Professional Development (in addition to mandatory training)

HR 31st Jan 2019 – GSTT Recruitment training half day include diversity/unconscious bias

HR and RM 8th Feb 2019 1 day - Compassion Focussed Therapy in Physical Health SIG, Homerton Hospital

HR and RM 19th June 2019 1 day- KHP Psychology Conference, London

HR Jan 2020 – Current and Future Advances in SCD, London

HR 24th Feb 2020 1 day– Compassion Focussed Therapy for Complex Presentations, Milton Keynes

RM is undertaking a two-year Cognitive Analytic Therapy (CAT) practitioner training. She attends 12 training days per academic year (Fridays and Saturdays), termly seminars and has an honorary contract with IPTT in Lambeth where she sees training cases and participates in weekly supervision.

Within GSTT when diaries permit, team members attend monthly Acceptance and Commitment Therapy (ACT), Complex Cases peer supervision, systemic peer supervision, Schwartz Round, and KCL health psychology seminars.

Health and Care Professions Council

The HPS team's registration within the HCPC are currently all up to date.

Mandatory Training

The HPS team are up to date with all the Trust's mandatory training.

Performance & Development Reviews

The HPS team PDRs are all up to date.

Complaints

We are aware of no official complaints.

Risk Management

The HPS regularly manages situations whereby patients disclose risk to self or others. This process can be very time consuming and can sometimes involve escorting a patient across hospital sites for urgent psychiatric assessment. The HPS team work in accordance with GSTT guidelines on managing risk to self and others, and GSTT Safeguarding Policies. We meet with the Consultant Liaison Psychiatrist every two months for consultation above and beyond that which is required on an ad hoc basis. This forms part of the stepped-care approach which involves collaboration around complex patients and onward referrals for patients with mental health problems.