RED CELL NEWS

SELSE HCC Newsletter

December 2025

Welcome to issue 22 of Red Cell News

In this Edition:

SELSE HCC

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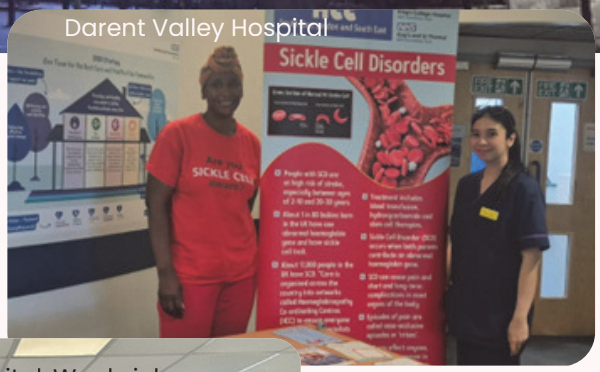
WORLD SICKLE CELL DAY & SICKLE CELL AWARENESS MONTH

World sickle cell day on 19th June 2025 and sickle cell awareness month was celebrated (in September) across the SELSE HCC network. Many hospitals had stalls and cakes to raise funds and spread awareness among hospital communities. King's College Hospital lit up red for the evening!

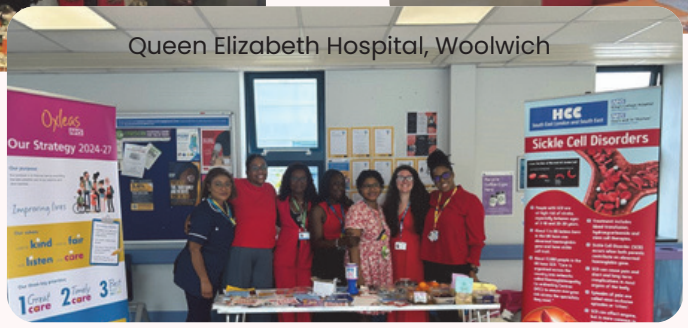
King's College Hospital

St Thomas' Hospital

Guy's Hospital



Darent Valley Hospital



Queen Elizabeth Hospital, Woolwich

Innovating Care Delivery: ED Bypass Unit at Lewisham

Transforming our services with an Emergency Department (ED) Bypass Unit opening by Lewisham and Greenwich NHS Trust (LGT) at University Hospital Lewisham (UHL)

Adults in Lewisham and Greenwich living with sickle cell disease are benefiting from the launch of an innovative Advanced Clinical Practitioner (ACP) led initiative at University Hospital Lewisham.

The ED Bypass Unit for Sickle Cell patients is designed to provide immediate and specialised care for patients experiencing sickle cell crises and related complications. This two-bed unit is the first its kind in the UK to be led by a team of ACPs with additional support from a consultant.

Located on the Laurel Ward, it serves as an Emergency Department bypass unit, reducing waits for treatment and pain management and is helping the Trust deliver on its target to treat patients within 30 minutes of their arrival at hospital.

"What this unit is going to do for patients in the local area is provide a single point of access for them in a time of crisis.

"We get to know the patients, they get to know us very well, and we'll know what their personal challenges are and be able to tailor our care to suit that patient instead of treating them as a template.

"It means they're being heard; they're being listened to and that we're there for them."

Michael Barns, Lead Advanced Clinical Practitioner for the ED Bypass Unit

During this initial phase, the unit will operate with a limited schedule, concentrating on weekday services from 9am to 8pm. The team are already planning their next steps, which include extending these hours to weekends, with the strategic goal of achieving 24-hour operations by early 2026.

Patients can be referred to the unit by colleagues from the Emergency Department, London Ambulance Service, and can also call the unit to speak with our expert sickle cell team. Those eligible and in need of treatment at the unit must first call ahead to allow the team to determine whether their condition is suitable for treatment at the unit and if a bed is available.

"This ED Bypass Unit for Sickle Cell patients is going to mean that the patients have direct access to a specialist team of advanced clinical practitioners. The patients will be able to access care almost immediately.

"The ongoing working relationship between patients, their families and the team is key to the success of the unit and aids in removing barriers to receiving the right treatment at the right time."

Dr Tullie Yeghen, Haematologist and Lead Haemoglobinopathy Consultant

As someone living with a rather severe form of sickle cell disease, navigating daily life and my career has required a delicate balance between managing my health and trying to maintain a sense of normalcy. The Introduction of the new Bypass Unit has been transformative in helping me manage periodic crisis whilst allowing me to quickly revert to my daily life.

"I would like to express my deep gratitude to the management team for introducing this new system as well as thanking Michael's team (Manuela, Shade, Sam etc) for their dedication, kindness, and professionalism in delivering this service. I hope that this service is maintained and expanded to benefit the wider community."

By streamlining the process and having a dedicated team, this has resulted in me receiving the required medication on a timely manner and in turn helping my pain level to dissipate quicker at low enough allowing me to return home the same day.

With a busy career and other obligations, this has so far been transformational removing the anxiety I used to feel about going to A&E, sometimes even delaying treatment out of dread. This has been replaced with confidence and relief. The unit has empowered me to seek help earlier, preventing escalation and reducing hospital stays.

Contributions by LGT news and Issac Serungoui

In Focus: Gene Therapy Breakthrough for Sickle Cell

Gene therapy has been approved by NICE for sickle cell disorder

On 9 April 2025 NICE approved the ground-breaking gene therapy, Exa-Cel (Exagamglogene Autotemcel), brand name Casgevy, for use through the NHS for people living with sickle cell disorder.
Clinical trials suggest Exa-cel can stop painful and unpredictable sickle cell crises – the most common symptom of sickle cell disease – where blood vessels become blocked causing severe pain, with experts saying the therapy offers patients a chance of disease-free life.
Researchers concluded that it provides a 'functional cure' in 96.6% of treated Exa-cel trial participants (source NHS England).
Gene therapy is an option for eligible patients who have had not been able to have other curative treatments because of a lack of a suitable donor. Only 50 people with sickle cell disease will be eligible for this treatment in the UK per year.

How it works:
These therapies utilise gene-editing technology, such as CRISPR, to modify a patient's own blood stem cells, aiming to restore the production of healthy red blood cells.

This new treatment could allow some patients to live a normal life with few or no restrictions caused by sickle cell disease. Although this is a great option for some it will not be an option for the majority due to the significant cost attached. It is important to speak to your specialist sickle team to see if you are eligible.

King's College Hospital is one of five centres in England chosen to provide this ground-breaking treatment, which has been based on scientific discoveries made at King's College London by Dr Stephan Menzel and Prof Swee Lay Thein.

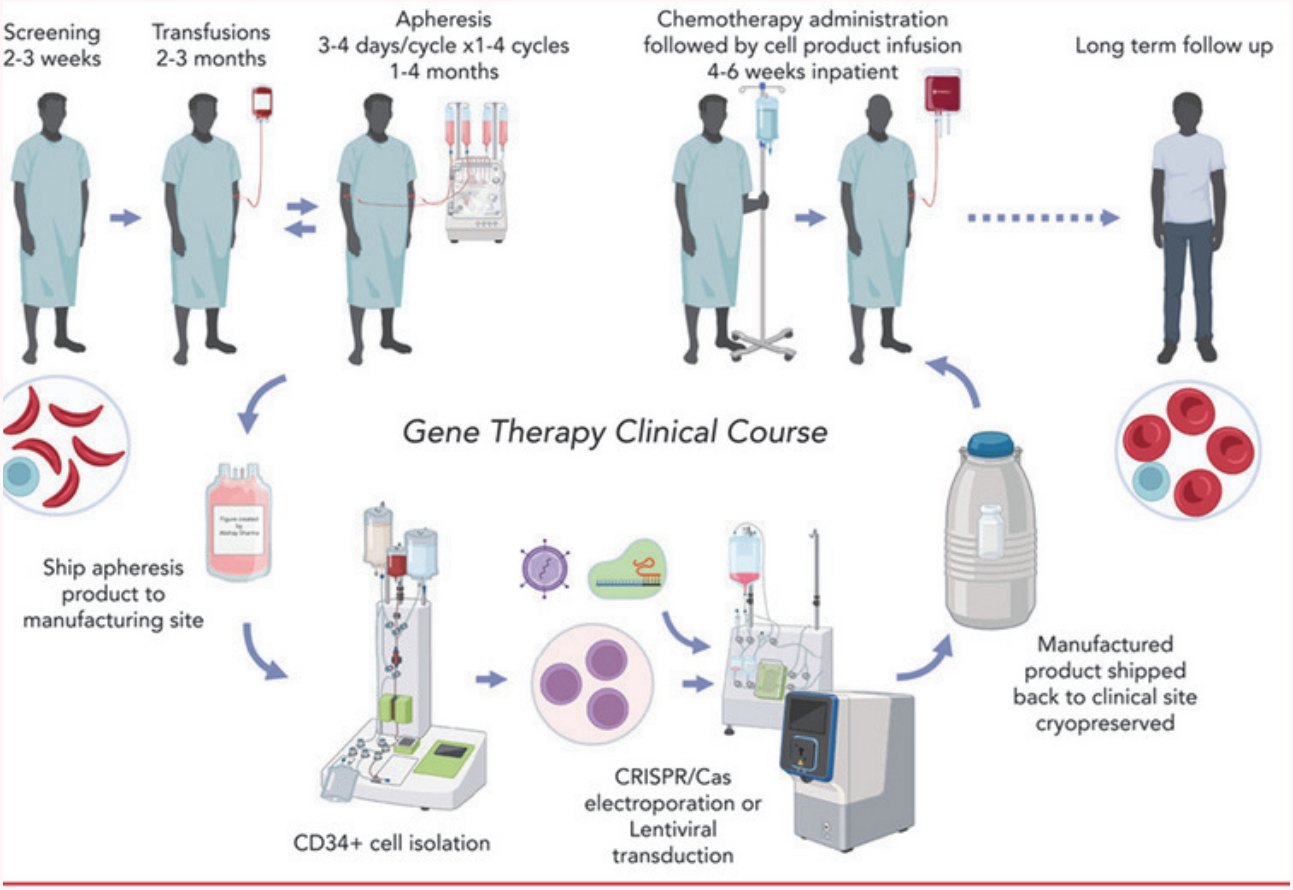


Image adapted from Sharma. DOI:10.1182/blood.202402

London Ambulance Service's research project to improve care for sickle cell patients

A research project commissioned by London Ambulance Service NHS Trust and the Sickle Cell Society into sickle cell patients' experiences of ambulance care and 999 & 111 calls in London was commissioned and released in April 2025.

London Ambulance Service (LAS) has unveiled a wide-ranging plan to further strengthen the care it provides to patients that are seriously ill with sickle cell disease.

London Ambulance Service attends approximately 5,700 callouts per year from sickle cell patients in London, which is the most prevalence area for the condition in the UK. As a service which is often the first point of contact for sickle cell patients in crisis, improvements to the service is needed and likely to play a significant role in improving outcomes for people living with sickle cell and as part of wider efforts to tackle health inequalities.

Our Croydon colleagues were included in a project to develop training resources for LAS and below Victor Emmanuel- CUH Trust Haematology Sickle Cell Patient Representative tells us how it went.

"My Experience Supporting London Ambulance Service Training"

As a patient representative of the Croydon Sickle Cell and Thalassaemia Support Group, I have long witnessed the immense challenges sickle cell patients face—particularly in emergency situations. Many of us have relied on the London Ambulance Service during painful crises, and while some experiences have been excellent, others have left patients in agony, misunderstood and unsupported.
That's why, on 2 April, I was pleased to take part in a training initiative at the LAS's training centre in London, helping to develop a video resource designed to educate paramedics and frontline staff on how to manage sickle cell patients effectively and empathetically.

Why this training was urgently needed
The London Ambulance Service has been under mounting pressure for years. Funding cuts, staffing shortages, and the aftermath of the Covid-19 pandemic have all taken their toll, stretching the service thin across the capital. Unsurprisingly, some vulnerable patient groups—like those with sickle cell disease—have experienced inconsistencies in care as a result.
Sickle cell disease is a complex and often misunderstood genetic blood disorder. One of its most distressing symptoms is the vaso-occlusive crisis—an episode where misshapen red blood cells block blood flow, causing sudden, intense, and debilitating pain. These episodes require immediate pain relief, hydration, and swift hospital transfer. Yet, sickle cell patients have frequently reported delays in care, suspicion around requests for pain relief, and an overall lack of understanding. Far too often, patients are met with doubt instead of support, exacerbating trauma during already distressing episodes.

A collaborative step forward
In response to these concerns, LAS reached out to the Croydon Sickle Cell and Thalassaemia Support Group to collaborate on ways they could improve on the services they provide to Sickle cell patients. A survey of patients encounter with the LAS was carried out by the group and a report submitted in September last year. The idea for a collaboration on the training resource was a direct result of this work. Their aim was to strengthen understanding among frontline responders, improve patient outcomes, and combat unconscious bias.

On the day of filming, I spent two hours at their London training facility, helping to shape a video that would be integrated into LAS's staff training. The session covered:

- An overview of sickle cell disease and its symptoms, particularly the nature of painful crises.
- Best practice for paramedics, including how to assess pain and recognise the urgency of the condition.
- The importance of listening and empathy, especially in avoiding assumptions such as labelling patients "drug-seeking".

I shared personal insights—recounting the excellent support I've received from some LAS crews, but also highlighting occasions where the pain and urgency of a crisis were downplayed or misunderstood. I emphasised the lasting impact those negative experiences can have on a patient's trust in the system.

What stood out to me was LAS's approach: open, respectful, and willing to learn. Their training team listened intently, asked thoughtful questions, and clearly wanted to understand the lived experience of those with sickle cell. That kind of genuine engagement is not something we take for granted.

Progress, but not perfection
Having used ambulance services many times and since the report was submitted, I can confidently say that progress is being made. There's a visible improvement in how some paramedics now respond to Sickle cell calls, and the very fact that LAS has initiated this training shows a shift towards a more inclusive and informed service.

However there's still more to be done:
1. Response times must improve. Sickle cell crises are time-sensitive, and delays can escalate complications.

2. Sickle cell training should be standardised and regularly refreshed, not offered as a one-off session.

3. Pain management protocols need urgent review. Patients should not have to plead for appropriate medication—there must be trust in what they say.

4. All the knowledge, trainings and collaborative work that is positively transforming the LAS in how they respond and care for sickle cell patients must be rolled out nationally.

What this collaboration means

This initiative is more than just a training video. It represents a commitment to change. It shows that services are beginning to value patient insight and are actively working to improve how they engage with historically underserved communities.
To the LAS, I offer sincere thanks. Taking this step, listening to our voices, and integrating real lived experience into their training is commendable.
To fellow sickle cell warriors: keep advocating. Every voice matters. Your experiences are valid, and your care should reflect that.

Contribution by Victor Emmanuel -CUH Trust Haematology Sickle Cell Patient Representative, Croydon Sickle Cell and Thalassaemia Support Group Member -CEO Westbrook Care Group

Peer Mentoring: Supporting the Next Generation

The peer mentoring programme is a London-wide initiative which pairs young sickle cell patients with mentors who have first-hand experience of living with the condition, offering them guidance on managing their health. In south east London, the scheme has been rolled out by the south east London Integrated Care System, in partnership with the Sickle Cell Society.
The pilot programme has been funded for two years by NHS England as part of a wider plan to support improvement of community services for those living with sickle cell.
The programme has been particularly successful in south east London, with more than 70 referrals so far.

Dr Dale Seviar is the lead clinician for the programme and a consultant haematologist at Guy's Hospital. He said:
"The peer mentoring program is an exciting programme for children and young people with sickle cell disorder. Trained mentors with sickle cell themselves are matched with mentees.
"The program aims to improve the health and well-being of young people with sickle cell disorder through peer support and to improve young people's understanding and management of the condition.
"We've had an excellent uptake for the programme across our network; we are enthusiastic about the difference this will make in the lives of our young people with sickle cell."

Some mentees were interviewed by ITV for their views on how the programme is working. When asked about her experience on the programme, 27-year-old Rachel Simpson, a lead mentor in south east London, said:
"Being able to share my knowledge about living with the condition and what has helped me manage it daily, has been truly fulfilling.
"Sickle cell has shaped me into the strong person I am today, and I'm proud to help other young people recognise their own worth and resilience as they navigate life with sickle cell."

Her mentee, 23-year-old aspiring actress Marilen Maddy said:

"I decided to join the program as a way connect with other people like me, people who share my pain and know exactly what it's like living with sickle cell.
"I love the fact that this program has mentors that actually have sickle cell, it's so relatable! When I met my mentor, we sat and spoke for hours and I've never felt so satisfied. I finally felt heard, and it was so reassuring to know that I'm not the only one suffering."

Clinicians can refer patients via the Sickle Cell Society website, patients and parents can also self-refer to the programme at www.sicklecellsociety.org/mentoring

Source South East London Integrated Care Systems' website

BLACK HISTORY MONTH
Legacy and Art: Remembering Donald Rodney

Donald Gladstone Rodney (18 May 1961 – 4 March 1998) was a British artist. He was a leading figure in Britain's BLK Art Group of the 1980s and became recognised as "one of the most innovative and versatile artists of his generation." Rodney's work appropriated images from the mass media, art and popular culture to explore issues of racial identity and racism

There was a free exhibition From February – May at Whitechapel Gallery showcasing the artist Donald Rodney. The exhibition was an extensive display of archive materials, which offers a rich context for Donald Rodney's life and work. From his early days as a student at Trent Polytechnic in Nottingham to his last solo exhibition at South London Gallery, the archive includes a range of visual elements that document the rigorous and often unconventional research methods that Rodney undertook to inform and develop his practice. It also shows how his creative process was shaped by his experience of living with sickle cell anaemia as well as his belief in collective working with colleagues and friends. The display notably includes photographic documentation of Rodney's lost works.

If you missed the exhibit you can visit Tate gallery in Kensington where some of his work is displayed or visit a page dedicated to him online at https://www.tate.org.uk/art/artists/donald-rodney-3076

Image of 'In the House of My Father' by

The photographic work In the House of My Father (1997), depicting a minuscule house made of the artist's skin, was shot in King's College hospital, London.

Welcomes and Farewells

We welcome and say goodbye to some new members to our SELSE HCC network team and partner organisations.

Welcome

James Clarke

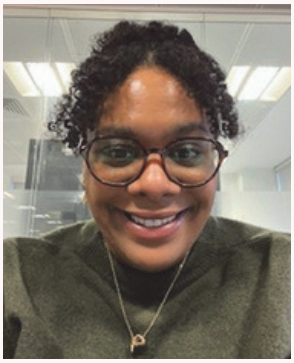
James is a Consultant Haematologist based in Kent, with over ten years of clinical experience across both Kent and London. His practice focuses on paediatric and non-malignant haematology, and he currently leads both the laboratory and clinical haemoglobinopathy services in East Kent. James is passionate about delivering compassionate, high-quality care to individuals affected by red cell conditions such as sickle cell disease and thalassaemia. He is dedicated to improving every stage of the patient journey—from urgent care to long-term support—ensuring that everyone receives the attention and respect they deserve.

Tara Flynn-Nickolds

Tara is a Clinical Psychologist and EMDR therapist with over ten years of experience within the NHS. She has worked across a range of clinical and community settings serving children, adults, and older adults throughout London and the Southeast of England.

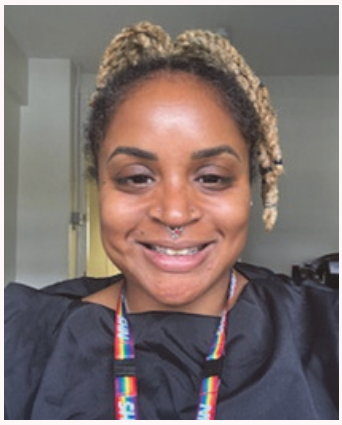
Her primary professional interest lies in clinical health psychology, with a focus on supporting individuals in managing psychological distress associated with chronic health conditions. Tara has a strong commitment to helping those affected by sickle cell disease and thalassemia to achieve their full potential and lead fulfilling lives. Dedicated to a holistic approach, Tara strives to ensure equitable access to psychological support.

Thera Broni



Thera is on a secondment as SELSE HCC Network coordinator and joined the team in January 2025. She is keen to learn and understand more about haemoglobinopathies. She has put together this newsletter for you.

Pia Baker



Pia a new Social worker covering the maternity leave of the substantive social worker at King's College Hospital. She has been a Social Worker for 11 years and recently worked for Grenfell for five years supporting the survivors and bereaved from the Grenfell Tower Fire as part of their recovery post trauma. Pia has Masters in Psychotherapy and Psychodynamic Counselling as well as a Social Work degree, and has a specialist interests in complex loss, bereavement, resilience and recovery.
'I am keen to continue building on the holistic approach to support patients in Haematology. I have a particular passion for those that do not currently access services due to barriers within their communities'.

Loretta Achiekwelu

Loretta is a project manager who's spent the last few years leading programmes and projects across the NHS. She is passionate about creating equity for marginalised groups and has led projects aimed at improving access and outcomes. She is now managing the South East London Sickle Cell Improvement Programme, overseeing delivery of enhanced community services across the six boroughs of Southwark, Lambeth, Lewisham, Greenwich, Bromley, Bexley, keeping track of what's working well, identifying gaps, and working closely with NHS Trusts, community groups, and organisations to make sure the service meets the needs of people living with sickle cell disorders.

FAREWELL & THANK-YOU!

After more than 20 years with our haematology service, we say a warm farewell to Dr Anandika Liyanage. She's been a hugely respected and much-loved member of the team—known for her incredible diligence, deep expertise across the breadth of haematology, and the genuine care she gave to each and every patient. Over the years, she has helped shape better services for people with red cell conditions and was always passionate about teaching and supporting haematology trainees. Her presence will be deeply missed, both professionally and personally, and we wish her all the very best for her retirement.

Professor Buba Inusa National Haemoglobinopathy Panel Chair 2020 – 2024 has moved into industry

Professor Baba Inusa was the founding Chair of the National Haemoglobinopathy Panel (NHP) from 2020 until March 2024 when he left the UK for a role in Denmark. Professor of Paediatric Haematology, King's College London and lead clinician at the Paediatric Sickle Cell service of Evelina Children's Hospital, Professor Inusa's experience in haemoglobinopathies and rare inherited anaemias is extensive and has positively impacted the haemoglobinopathy landscape nationally and internationally. He held an enduring clinical practice, oversaw national and international research projects, founded the internationally renowned Academy for Sickle Cell and Thalassaemia (ASCAT) and lead on the African Research and Innovation Initiative for Sickle Cell Education (ARISE). He is the Associate Editor of Journal of Sickle Cell Disease and a member of the World Health Organisation (WHO) expert group on centres of excellence for Sickle Cell Disease in Africa. He has co-authored over 130 papers and edited 2 books on Sickle Cell Disease.

While NHP Chair, Prof Inusa dedicated his personal and professional time and resources to develop the NHP and its network. His drive, skill and goodwill galvanised colleagues and fostered engagement amongst members, shaping these relationships into a well-connected, functioning, relevant and value-giving network. During MDT meetings, he was often a grounding force, drawing out learning, referring issues to key evidence and ensuring there was input from the appropriate non-haemoglobinopathy experts as each case required. His engagement with other organisations such as the Sickle Cell and Thalassaemia All-Party Parliamentary Group (SCT APPG and the Sickle Improvement Steering group ensured a national clinical and patient perspective was represented in such vital platforms.

Wonderfully underpinning all this is Prof Inusa's capacity for empathy and understanding, to drawing out the best in people to aid their personal and professional development. Undoubtedly, these are the qualities that resulted in him developing friendships in every environment in which he engaged.
Professor Inusa will be genuinely missed in the NHP team, network and his wider NHS associations, including patients. However, his great efforts and vision have been, and will continue to be, of benefit to many in the haemoglobinopathy community, with immense appreciation.

Support Groups and patient representatives

Please find below the details of how to join us for the Virtual Sickle Cell Support Group for patients and carers in your local hospitals.

Guys and St Thomas' Hospital

Time the group meets: Every Thursday from 1-2pm
Link to join: https://bluejeans.com/540502643/0189
If required, please enter: Meeting ID: 540502643
Participant Passcode: 0189

King's College Hospital

Adults
Patient representative – Lola Vito
Patient representative contact information – Email: lolavito@hotmail.co.uk
Time the group meets – First Thursday of each month
Location - Via Microsoft TEAMS online (please contact the patient rep for the link)
Parents
Contact: Clinical Nurse Specialist - Agnes Temba
020 3299 4752 email kch-tr.paedhaematologycns@nhs.net
Meets every second Thursday of the Month at 12-1pm on Microsoft Teams to learn more about sickle cell and thalassaemia and have the opportunity to meet with other parents and share experiences.
Please email kch-tr.paedhaematologycns@nhs.net to get the Microsoft Teams link

Croydon Hospital

Adults
Patient representative - Mr Victor Emmanual
Patient rep contact information - 07956311279 Email: murzit@googlemail.com
Time the group meets - Every second Saturday of the month between 3- 5pm
Location - Via Zoom online (please contact the patient rep for the link)

Lewisham & Greenwich

Email contact - lg.sicklethalpsychology@nhs.net
Time the group meets - First Wednesday of each month, 5.30-6.30pm
Location - Via Microsoft Teams online
Please scan the QR code, fill in your contact details and you will be sent a link

Thank you for reading this issue.

Please check our website **www.selsehcc.org.uk** for upcoming events.

If you have any stories, events, comments or suggestions for the next newsletter, please send them to: **selsehccadmin@nhs.net**