Homerton Healthcare
NHS Foundation Trust

Patient Voices – Sickle Cell Care in Hackney – What has changed 10 years on?

1.0 Background

This paper is in response to a published Healthwatch Hackney report following a review by them of the Sickle Cell services at Homerton Hospital between June and November 2025.

Feedback was gathered from people living with sickle cell disease and the some of the staff caring for them.

The review included a focus group, held in June 2025, where 16 participants shared their experiences of accessing care outside hospital settings, including GPs and Emergency Department (ED); an enter and view visit to Lloyd Ward at Homerton Hospital in July 2025, where they spoke with three staff members and the only 2 sickle cell patients in the ward on that day.

An enter and view visit to the Medical Day Unit (MDU) in November 2025, where they spoke with 8 patients and 3 staff.

The report found that patient experience of sickle cell care varies depending not on clinical need but on where care is accessed. This creates, in the words of a patient, a "*postcode lottery*" within the system.

Based on all the evidence collected on sickle cell patients' experience of care, findings, and observations, Healthwatch Hackney would like to make the following recommendations.

Recommendations to Homerton Hospital NHS Foundation Trust

1. Improve patient experience and trust in ED
   Review and strengthen standards for how people with sickle cell disease should be treated in ED
   Strengthen awareness of sickle cell care plans and escalation routes in ED
2. Address racism, stigma, and bias through explicit reflective practice
3. Protect, sustain, and share learning from the Medical Day Unit (MDU) model
4. Address the practical constraints of space and privacy in the MDU
5. Strengthen communication with patients throughout their stay
6. Deepen reflective work on racism, stigma and bias

2.0 Homerton Service

The sickle cell and thalassaemia services are an integrated service delivering acute and community care for patients with sickle cell and thalassaemia disorders for residents of city and hackney. The service provides a holistic multi-disciplinary

approach to patients and their families living with these complex lifelong conditions. The service is unique in that it provides a service across the life span. The services integrated model was revered by the west midlands quality review service and has resulted in services across the country trying to replicate the Homerton model. We have a comprehensive MDT comprising of specialist nurses - both adults and paediatrics, a specialist midwife, social liaison advisor, welfare and benefits advisor and psychotherapy services.

The Homerton is a specialist centre for sickle cell and thalassaemia with Essex trusts feeding in for patient advice and support with complex patient management. We currently have approx. 450 adults and 170 children on our caseload. We have shared care arrangements with the Royal London Hospital where our children are seen until they are 16 when they transition to local adults' services. The service is responsible for processing all the carrier and affected results as part of the newborn screening programme. The team are responsible for developing and supporting the creation of care plans for patients in multiple settings including, school, college, and university. We provide training for learning and development for Nurses, GP's, AHP's, local stakeholders including hackney council etc.

The report identifies our Medical Day Unit (MDU), care is consistently excellent. 100% of patients on the day of our visit described the MDU as safe, welcoming and trustworthy. Patients told us they were believed immediately, assessed quickly and treated within 30 minutes. No patients raised concerns about the quality of the clinical care at the unit.

Our senior nursing staff are based within the Integrated Acute and Community service rotated across multiple sites, which enabled staff to have a diverse skill set and ensured seamless integration between inpatient and community services. This approach had enabled the service to deliver a comprehensive, patient-centred model of care. Its success had set a strong precedent, inspiring other services to adopt and replicate similar strategies within their own practice.

We provide opportunistic screening and genetic counselling as well as raise awareness across the borough for sickle cell and thalassaemia disorders, including teaching for schools and colleges as well as local projects, health fairs and places of worship. We feed into the neighbourhoods for patients in C&H. We provide pre and post hospital follow up. Including interventions to support home care and reduce the need for acute presentation. We have a specialist medicines clinic run by the Nurse Consultant & Advanced Nurse Practitioner which is solely for disease modifying therapies looking at improving patient outcomes.

We continue to work closely with our GPs to ensure a collaborative approach to the management of our sickle cell patients. Clinical leadership in City & Hackney is currently being reviewed due to changes to integrated care boards. In future clinical leadership models, the aim is to have a primary care clinical lead who has sickle cell disease in their portfolio. This role was previously held by Dr Jenny Darkwah for Adults and Dr Ben Saw for paediatrics. This clinical lead will be able to link in with the Homerton team and support further MDT collaboration and case reviews. There is an understanding we need to tighten communication between our service at the

Homerton and with our local GPs, especially around care plans and analgesia. This is hopefully strengthened by the recent introductions of the urgent care portal which is accessed by both acute and community providers as well as London ambulance service detailing patient care plans. We will continue to develop a regular programme of training that will meet the needs of our GPs and staff to support addressing gaps in knowledge to support improved management of this patient group.

The team do have well-established pathways within the primary care setting for acute and chronic disorder management. This includes GP pathways for adult and paediatric guidance. The team had fostered good relationships with the local ICB and GP network and regular training and development sessions were delivered and reported as attracting high engagement from GPs and patient representatives, who actively participated in these sessions. The education sessions were available on the City & Hackney GP website for further reference and information alongside the clinical pathways.

3.0 Recommendations from Sickle Cell care in Hackney Report & Homerton's actions to address.

Recommendation	**Homerton's Action to address**
Homerton Hospital should review and strengthen clear standards for how adults with sickle cell disease are received, listened to, and supported in ED, focusing on respect, belief, and communication. This should include: ● Treating patient-reported symptoms as credible and prioritising listening over visual assessment of distress. ● Ensuring staff explain delays, decisions, and next steps clearly and regularly, particularly during long waits. ● Avoiding language or behaviour that implies suspicion, blame or assumptions about drug seeking.	Staff training and communication to support raising awareness has included the need for all staff to ensure they listen to the patient and provide the patient time to discuss their symptoms and level of pain being experienced. The team have also been asked to ensure they ask our sickle patients that present, for regular updates with regards to pain relief following analgesia administration. All staff have been asked to focus on clinical needs and not make assumptions. Delays encountered need to be communicated clearly and consistently with patients. Pain management plan to be clearly discussed with patient on presentation, patients to be informed who to escalate to during the shift if they are feeling unheard or their pain management not getting addressed.

Inadequate staff training and sickle cell awareness	Trust-wide Sickle Cell Awareness and Clinical Management Training Programme, co-designed and delivered with the Sickle Cell & Thalassaemia team, incorporating patient voices and case studies. This will include: ● Core e-learning embedded into the mandatory training schedule, as already being developed by Lead Nurse Consultant ● Clear competency framework and alignment with existing policies to remove inconsistencies with Patient Controlled Analgesia (PCA) ● Regular review of training uptake and impact as part of the annual Training Needs Analysis.
Strengthen awareness of sickle cell care plans and escalation routes in ED ED staff should be supported to quickly identify and act on existing sickle cell care plans and escalation pathways to specialist care, so that patients are not required to repeatedly justify their needs or explain their condition while in pain. Where specialist services are available, this should be clearly signposted and used proactively.	The ED Department are working closely with the EPR team to improve visibility and accessibility of care plans by ensuring sickle cell care plans are clearly flagged in electronic patients records. The team are standardising where care plans are stored so staff do not need to search across multiple systems. This should be made easier with the introduction of the urgent care portal. The team are undertaking short, targeted training on recognising sickle cell crisis, understanding care plans and knowing when to escalate as part of their mandatory training. A quick reference guide, flow chart has been developed to make it visible for ED staff so the appropriate escalation to the specialist team occurs. Staff awareness of when to escalate to the Haematology team has been shared.

	Staff have been asked to ensure they rely on documented care plans and clinical indicators rather stereotypical assumptions The ED team have been asked to promote a culture of trust, empathy and timely analgesia for our Sickle patient group. Improved training and awareness at safety huddles continues.
Address racism, stigma, and bias through explicit reflective practice The Trust should introduce regular reflective learning sessions for ED teams focused on: ● Sickle cell patient experiences of stigma, disbelief, and stereotyping. ● The impact of assumptions about pain, behaviour, and opioid use. ● Learning from complaints, PALS feedback and national evidence on racism in sickle cell care.	At Homerton Healthcare we are fully committed to being an anti-racist organisation and make clear that racism, in all its forms, has no place in our organisation. We are embedding anti-racism as strategic priority at Board level, and we are working in partnership with our Staff Networks to deliver key actions to the wider organisation such as: ● Cultural Intelligence and Active Bystander training. ● Inclusive Recruitment training for hiring managers. ● Triangulation of key data sources to identify hotspot areas for targeted intervention. ● Review and refresh of trust wide policies and procedures through an anti-racism lens. ● Refreshed approach to talent management and succession planning, including targeted leadership development programmes to support progression for underrepresented staff. ● Requirement for every person in a management and leadership role to agree a specific anti-racism related objective. Our EDI Lead is working with ED teams to deliver training for nurses and doctors, which includes anti-racism and

	automatic bias. Training begins from 11th March 2026
Protect, sustain, and share learning from the Medical Day Unit (MDU) model	We are exploring the feasibility of expanding the opening times of MDU to improve access and better meet patient needs. We continue to recruit and train our workforce to ensure staff have the skills and expertise required to provide high quality, safe and compassionate care. We will share positive feedback and learning from MDU to the wider clinical areas by working with the Sickle Cell & Thalassaemia team to share this learning through training and structured patient voice mechanisms.
Address the practical constraints of space and privacy in the MDU The Trust should review the suitability of the current space to ensure that the environment supports patients' dignity, comfort and confidentiality and does not undermine their otherwise positive experience.	We have acted on feedback regarding space limitations, patient comfort and privacy. Expansion of MDU2 has already been rolled out, additional treatment chairs and divided curtains are in place, and we are pursuing capital funding for recliner chairs to better support patients experiencing pain or mobility limitations during sickle crises. These enhancements directly address patient-reported comfort needs and will help preserve the high standard of care the unit provides.
Lloyd Ward - Strengthen communication with patients throughout their stay Lloyd Ward should continue to improve the consistency and clarity of communication with patients, particularly around pain management, delays, and discharge planning.	The Ward Manager is liaising with the Education team and exploring training available to improve communication between staff and patients. Practice Development Nurse and Ward Manager are reviewing suitable options for the team recognising the need to strengthen communication support for staff, for all patients on the ward. This will be incorporated into the Ward Development Days that are focused on training that directly responds to the specific needs identified on the ward.
Deepen reflective work on racism, stigma, and bias The ward should build on existing reflective practice by continuing	Our EDI Lead is working with the ED teams to embed ongoing reflection and learning from anti-racism and automatic bias training with a plan to deliver in March/April 2026.

structured opportunities for staff to explore how stigma, assumptions and unconscious bias can affect patient experience, particularly for people with sickle cell disease. This work should focus on learning and culture change, not individual blame and draw directly on patient feedback.	We have a bespoke training plan in development to support increasing awareness of sickle cell disease to help reduce misconceptions and stigma. We know that effective stigma management for patient with sickle cell disease involves a multifaceted approach, combining education, support and advocacy. We will continue to work with our teams to ensure every patient and person is respected, valued and treated equitably.
Address and ensure compliance with NICE clinical guidelines re delivery of pain relief within 30 minutes for sickle cell patients?	We continue to undertake monthly audits of compliance with this NICE recommendation. We are aware our compliance with achieving the 30min pain relief KPI is not fully being achieved, we are working with the team to urgently address. We are working with assessment nurses to promptly prioritise the assessment of our sickle patients on presentation. Clinical observation will be taken along with documentation of pain assessment. The assessment pathway has been reviewed; the assessment nurse has been asked to escalate the need for the patient to have a prescription to the Nurse in charge (NIC) in majors so we can ensure timely administration of pain relief. We are also with the team to ensure nurses have completed their PDG's for sickle cell after 1 year post registration. NIC to ensure that a nurse is allocated to administer medication promptly. We are hoping with the review of this pathway and assessment we can administer the required pain relief within the 30min window.
Improve the experience for our transition patients from Paediatrics to Adult services	Our Transition pathway is currently suspended; there is some work required to re-establish a transition pathway and to ensure there is sufficient staffing in the adult and paediatric teams to

	provide appropriate support and facilitation to enable the safe transitioning of young people living with a haemoglobin disorder.

4.0 Patient Involvement & Engagement

The Trust has an established patient-led support group, Solace. We will continue to meet regularly with the Solace group to provide updates and share progress on the actions arising from the Healthwatch report. These meetings will also be a forum to discuss proposed service changes or improvements and to ensure that any collective concerns raised by patients are addressed. The service remains committed to co-designing care with meaningful patient involvement, ensuring that developments reflect and respond to the needs of the people we serve.

5.0 Conclusion

At Homerton we have a dedicated team that are continuously working to maintain current good practice by continuing to listen to our service users and their families and providing good quality and culturally competent care closest to home.

We will continue to be actively involved in driving improvement and innovation and ensure all our staff caring for this vulnerable group have the skills, knowledge and understanding to deliver safe effective patient centred care.