healthwatch Hackney

2025

PATIENT VOICES: SICKLE CELL CARE IN HACKNEY

WHAT HAS CHANGED 10 YEARS ON?

Content

Executive Summary

In 2015, Healthwatch Hackney published a report highlighting significant problems in sickle cell care at Homerton Hospital, including poor staff attitude, inadequate pain relief and concerns on cleanliness. This research serves as a follow-up, to evaluate whether patient experience has improved and identify where care requires further improvements.

What we did

Between June and November 2025, we gathered evidence from people living with sickle cell disease and staff caring for them. This included a focus group, held in June 2025, where 16 participants shared their experiences of accessing care outside hospital settings, including GPs and A&E; an enter and view visit to Lloyd Ward at Homerton Hospital in July 2025, where we 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 we spoke with 8 patients and 3 staff.

We analysed all feedback to identify patterns, compared findings with our 2015 report and examined how experiences vary across different care settings.

What we found

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.

In non-specialist settings like A&E and GP surgeries, care is poor. 88% of patients in the focus group reported being disbelieved about their pain in A&E, with decisions based on how someone looked rather than their symptoms.

Waiting times for pain relief ranged from 1.5 to 6 hours, far exceeding the 30 minutes NICE standard. 94% of participants raised concerns about their GP's knowledge of sickle cell, with some GPs asking whether patients were born with sickle cell or married to their cousin. This shows both ignorance and cultural stereotyping. 81% of patients shared that their GP refuses to prescribe pain medication despite clear hospital documentation. 75% of patients stockpile medication because they cannot reliably access prescriptions, despite knowing that this practice is not safe.

On Lloyd ward, care has improved since our last visit. In 2015, patients described staff as rude, malicious and spiteful; in 2025, they described staff as professional and trying their best. Concerns over cleanliness have been addressed and pain relief monitoring has been implemented. However, patient experience still varies depending on which staff are on duty. Patients told us that haematology specialists are generally more responsive than non-specialist or on-call staff. Neither of the patients we spoke to in the ward received pain relief within the 30 minutes NICE guidelines. Communication around discharge remains problematic, leaving patients unsure about what was happening.

At the 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. Patients identified overcrowding and lack of privacy as the only areas of improvement. One patient stated that the MDU "*should act as a blueprint for other wards*".

The MDU shows that there are five factors that enable excellent sickle cell care. First, specialist knowledge is concentrated in a dedicated team. Staff at the

MDU deeply understand the condition and can act confidently. Second, continuity of care. The very limited staff turnover means that staff and patients develop a sense of familiarity, which helps build trust and facilitates prompt decisions. Third, staff are trained and empowered to act quickly. This autonomy means that, when needed, trained nurses can administer pain relief without waiting for a doctor's authorisation, which helps meet the 30 minutes NICE guideline. Fourth, the unit thrives on a culture of trust and belief, whereby patients are treated as credible and experts in their own condition. Fifth, there are clear protocols, that staff follows consistently. Everyone knows what to do, which gives patients a sense of predictability and security.

Our findings mirror the 2021 parliamentary inquiry on sickle cell care, which documented identical problems nationally: low awareness of the condition among healthcare professionals, routine failure to meet NICE pain relief standards, stigma, disbelief and inadequate training. It means that these problems are not unique but reflect how healthcare systems nationally are organised, staffed, trained and funded.

We also found that the transition from pediatric to adult services is particularly negative. All participants who discussed it described receiving good care as children but experiencing a sharp, poorly managed transition to adult services that were dismissive and adversarial. This created a deep lack of trust that persisted for years.

Finally, patients told us that racism still underpins many of these failures. As the parliamentary inquiry documented, negative attitudes toward sickle cell patients often reflect false beliefs about Black people having higher pain thresholds or being drug-seekers. 50% of the participants in the focus group described being labelled as drug-seeking when requesting appropriate pain relief.

Recommendations

Based on all the evidence collected on sickle cell patients' experience of care, our 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 A&E

1.1 Review and strengthen standards for how people with sickle cell disease should be treated in A&E

Homerton Hospital should review and strengthen clear standards for how adults with sickle cell disease are received, listened to and supported in A&E, 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.

Rationale: This recommendation responds directly to repeated patient reports of disbelief, dismissal and fear when attending A&E.

1.2 Strengthen awareness of sickle cell care plans and escalation routes in A&E

A&E 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.

Rationale: Patients' experiences show that inconsistency in recognising and following care plans is a major source of distress and delay in emergency settings.

1.3 Address racism, stigma and bias through explicit reflective practice

The Trust should introduce regular reflective learning sessions for A&E 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.

Rationale: Patient insight makes it clear that training alone is insufficient without explicit attention to tackling racism, bias and stigma.

2. Protect, sustain and share learning from the Medical Day Unit (MDU) model

The Trust should actively protect and sustain the MDU, recognising it as a model of good practice in sickle cell care. The Trust should also consider how learning from the MDU's approach to communication, patient empowerment and responsiveness could inform practice in other settings, including A&E and inpatient wards.

Rationale: Patient feedback showed that the MDU model supports humane, responsive and effective care for sickle cell patients.

3. 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.

Rationale: While patients expressed very high confidence in the quality of care provided at the MDU, the main concern raised was the physical environment, particularly crowding and lack of privacy.

Recommendations to Lloyd Ward

1. 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.

Rationale: Patients told us that uncertainty about what was happening contributed to anxiety and frustration, even when staff were trying to help. Clear explanations, regular updates and opportunities for patients to ask questions would help reduce distress and improve trust.

2. Deepen reflective work on racism, stigma and bias

The ward should build on existing reflective practice by continuing 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.

Rationale: While patients recognised that care on Lloyd Ward has improved over time, some still reported feeling stereotyped.

Recommendations to North-East London Integrated Care Board (NEL ICB)

1. Improve access, consistency and confidence in care provided by GPs

1.1 Improve GPs' understanding of sickle cell disease and patient pathways

The ICB should work with GP practices to improve their knowledge and awareness of sickle cell disease, focusing on:

- Understanding sickle cell patient lived experience of pain and crisis.
- Knowing when and how to follow hospital discharge letters and care plans.
- Recognising when reluctance to prescribe or refer creates avoidable harm.

Rationale: Participants consistently described GPs’ knowledge gaps as a key reason for disengaging from primary care altogether.

1.2 Reduce avoidable reliance to A&E

GP services should be supported to act as a reliable first point of contact for people with sickle cell disease, particularly around repeat prescriptions, referrals and early intervention. Where GPs are unable or unwilling to support patients, this should trigger review and support rather than leaving patients with no option but A&E.

Rationale: Failures in primary care directly increase pressure on emergency services and worsen patient outcomes.

1.3 Involve sickle cell patients in designing improvements to GP access

People living with sickle cell disease should be involved in shaping GP-level service improvements, including how appointments, prescriptions and communication are managed.

Rationale: Improvements supported by lived experience will help rebuild trust and ensure changes reflect real barriers experienced by patients.

2. Improve consistency across points of entry into the system

2.1 Reduce variation in experience based on where patients present

The Trust and ICB should work together to reduce the sharp drop-off in patient experience between specialist and non-specialist settings. This includes:

- Learning from what works well in specialist services (such as the MDU).
- Where possible, apply those principles to first-contact services like A&E and GPs.

Rationale: Patients' experiences suggest that care is too often shaped by setting rather than need, leading to avoidable harm and distress.

3. Improve coordination and support during the transition from paediatric to adult sickle cell care

The Trust and ICB should work together to improve patient experience and reduce long-term distrust. They should review how transition is currently managed and consider ways to ensure:

- clearer communication about what adult services involve and how care will change
- better coordination between paediatric and adult teams, so patients do not feel they are starting over
- additional support during early adult care, recognising that patients are expected to manage more complex systems at a vulnerable stage of life

Rationale: Participants in the focus group consistently described this transition as poorly managed, distressing and, in some cases, traumatic, with a sharp decline in feeling listened to and supported once adult care began. Improving this transition would help build trust earlier, reduce the burden of self-advocacy and support more positive engagement with adult services over time.

What is sickle cell disease?

Sickle Cell Disease (SCD) is a condition in which red blood cells take on a sickled shape due to a mutation in the haemoglobin gene. The rigid and misshapen red blood cells can obstruct blood flow, resulting in extreme pain, infection, anaemia and organ damage. The condition is genetic and individuals with sickle cell have it from birth. To inherit it, two copies of the gene must be passed down; it is possible to be a carrier but experience no symptoms.

Individuals with sickle cell experience painful episodes termed sickle cell crises. Crises are severe periods of pain that can affect various parts of the body. Additionally, they are subject to an increased risk of serious infections, typically in their blood, lungs, kidneys or bladder. Untreated infections or complications can lead to death.

There is no cure for Sickle Cell Disease but some aspects of it can be managed through blood transfusions, pain management, medication and, in some cases, stem cell or bone marrow transplants. Currently, there are ongoing health initiatives that aim to raise awareness, improve diagnosis and develop new treatments.

There is a high prevalence of sickle cell disease in African, Caribbean, Mediterranean, Middle Eastern and Indian populations. In the UK, approximately 18,500 people are diagnosed with sickle cell[1], making it the most commonly inherited blood disorder. Of them, approximately half are concentrated in London[2]. While the exact number of patients cared for at Homerton Hospital is not known, the hospital is considered a high-prevalence centre for the care of sickle cell patients.

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[1] Sickle Cell Society, 2025. About Sickle Cell. Available at: https://www.sicklecellsociety.org/about-sickle-cell/

[2] One London, 2024. Two thirds of Londoners with sickle cell disease have a Universal Care Plan. Available at: https://www.onelondon.online/two-thirds-of-londoners-with-sickle-cell-disease-have-a-universal-care-plan/

Purpose of this research

In 2015, Healthwatch Hackney published a report on Sickle Cell care in the Lloyd Ward, Medical Day Unit (MDU) and Acute Care Unit (ACU) at Homerton Hospital. The report highlighted issues in sickle cell care resulting from overstretched staff and stigma surrounding the condition. Key concerns included cleanliness standards, staff attitudes, access to pain relief and lack of coordinated care across different service providers.

This research serves as a follow-up, aiming to evaluate to what extent patient experience of sickle cell care has improved.

Methodology

This research builds on our previous work and sets out to explore the patient experience of sickle cell care both within hospital settings and for outpatients, to assess whether and how care has changed over the past decade.

Preparation

To prepare for the study, we reviewed a range of existing evidence, including the 2021 "*No One's Listening*" report by the All-Party Parliamentary Group on Sickle Cell and Thalassaemia; Healthwatch Hackney's 2015 Enter and View report on Sickle Cell Care at Homerton hospital; follow-up documentation from 2016 and 2020 showing actions taken in response to our 2015 report; online materials published by Homerton Hospital about their sickle cell services and sickle cell patients' feedback shared directly with Healthwatch Hackney.

This background research helped us identify the most important themes to investigate, including staff behaviour and understanding of sickle cell disease, timeliness of pain management, adherence to care plans, cultural competence and stigma surrounding the disease. These themes guided the development of interview questions used in our research.

Data collection

To explore the patient experience outside hospital inpatient settings, we hosted a two-hour focus group in collaboration with Solace, a patient-led organisation that provides peer support, advocacy and outreach for individuals with sickle cell disease and thalassaemia. The focus group took place in a hybrid format at the Matthew Duncan seminar room within Homerton Hospital, with eleven participants attending in person and five joining online (total n=16). The hybrid format was chosen to maximise accessibility and enable participation from people who might have been unwell, had mobility constraints or found it difficult to attend in person. Participants were invited through Solace's existing networks and included people living with sickle cell disease, some of whom also had caring responsibilities for others with the condition.

The focus group provided an opportunity for participants to share their experiences of accessing care as outpatients, including support from GPs and A&E. Participants were encouraged to share both positive and negative experiences.

To explore the patient experience of in-hospital care, we conducted two Enter and View visits at Homerton Hospital. The first visit took place at Lloyd Ward on 10 July 2025 and the second at the Medical Day Unit (MDU) on 6 November 2025.

Healthwatch Hackney has a legal power under the Health and Social Care Act 2012 to visit health and social care services and observe them in action. This power of *Enter and View* allows us to engage directly with service users and staff, providing a unique opportunity to assess both what is working well and where improvements could be made.

Lloyd Ward is a haematology ward that treats patients with sickle cell disease, thalassaemia, other haematological conditions, as well as endocrinology and general medical patients. During our visit, we spoke with two patients (the only two sickle cell patients on the ward that day), the matron of the Acute Care Unit, who was covering the ward that day, and a junior sister.

The Medical Day Unit (MDU) provides care for adult patients with a wide range of haematological conditions. Here patients can access diagnostic tests, such as bone marrow examinations, planned therapeutic interventions such as transfusions and drop-in reviews of acute pain for registered sickle cell patients. Patients can self-refer or be referred by their GP. During our visit, we spoke with eight patients receiving day care treatment for sickle cell and three staff members, including two senior nurses and a receptionist.

Across both enter and views, we collected information through direct observation of interactions between staff and patients, focusing on professionalism and respect for patient privacy and dignity. We interviewed patients and staff, asking mirroring questions to understand care from the perspective of both patients and staff and to evaluate where and why their perspectives differ. Finally, we used a checklist to evaluate the wards environment, including accessibility, cleanliness and overall atmosphere. We used the knowledge gained in our background research to inform our questions and observations.

To minimise disruption to the wards' operations, we notified ward managers via email one week before each visit and provided a digital version of the notification leaflet, requesting it be displayed in the wards to inform patients in advance.

Data analysis

All notes gathered from the focus groups and the enter and view visits were subjected to qualitative analysis.

First, we read through all the feedback from patients and the notes from our discussions with staff and the wards managers. This enabled us to gain an overall sense of what sickle cell patients were saying about their experience of care. Then we went through each piece of feedback and highlighted important points such as stigmatisation of patients, pain management, barriers to care and experiences of care in different settings. We labelled each of these points to help us organise the information effectively.

After this, we grouped similar points together to identify broader themes and returned to the original feedback to make sure they accurately reflected what people said.

Finally, we compared what patients shared with what staff and the wards managers told us. This ensured that the themes captured both patient experiences and the operational reality of caring for a sickle cell patient, providing a comprehensive view.

Our analysis was guided by four questions:

1. To what extent are accounts consistent across patients and settings?
2. Where does patient experience differ and why?
3. How has patient experience changed since our 2015 report?

4. How do local findings compare with national evidence, including the 2021 parliamentary enquiry on sickle cell and other published research?

Limitations of our research

While this research provides valuable insights into the patient experience of sickle cell care, several limitations should be acknowledged.

Sample size. We recruited participants in the focus group through Solace, a support group for people with sickle cell disease. This means participants were self-selected, already engaged with peer support and potentially more confident in articulating their experiences than patients who are not connected to such groups. Patients who have completely disengaged from healthcare services are unlikely to have participated. During our visit at Lloyd ward, only two patients with sickle cell disease were present and willing to speak to us. This small sample means our findings at Lloyd ward should be understood as indicative only. However, the accounts we heard were consistent with themes raised in the focus group and in previous reports. Similarly, while eight patients spoke to us during our MDU visit, this represents a single day's attendance and may not capture the full range of patient experiences across different times and levels of service pressure.

Clinical environment and power dynamics. Conducting research in clinical settings introduces several challenges. Many patients during Enter and View visits were acutely unwell, in significant pain or emotionally distressed. This affected how long they were able to speak to us, the depth of their responses and their emotional capacity to recount difficult experiences. As we prioritised patient wellbeing and clinical care needs over data collection, some interviews were necessarily brief. Additionally, patients may have felt reluctant to criticise care while still receiving treatment and being dependent on staff. Some may have moderated their feedback due to fear of repercussions. Conversely, staff being observed may have presented care in a more positive light than usual practice. This can lead to social desirability bias in both patient and staff responses[3]. To mitigate this risk, we clearly explained Healthwatch's independence from the hospital, assured participants of anonymisation and cross-referenced accounts across patients and settings.

Despite these limitations, we have confidence in our findings for several reasons. First, consistency across resources meant that the same themes emerged repeatedly across the focus group, the visit to Lloyd Ward and to the MDU, despite different participants, settings and timeframes. Second, our findings align with issues identified in our 2015 report, consultations in 2016 and 2020 and with national evidence, especially the 2021 "No One's Listening" parliamentary inquiry, which gathered evidence from hundreds of patients and clinicians nationally. Issues such as delayed pain relief, disbelief about symptoms, poor GP knowledge and the burden of self-advocacy were identified as national patterns, not issues unique to Homerton Hospital. Lastly, collecting data from patients, staff and through direct observation and comparing these perspectives enabled us to build a more complete picture than any single method would provide.

This means that our findings remain valuable for identifying where care is working well, where patients are experiencing harm and what needs to be improved.

Ethical considerations

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[3] Bergen N, Labonté R. "Everything Is Perfect, and We Have No Problems": Detecting and Limiting Social Desirability Bias in Qualitative Research. Qual Health Res. 2020 Apr; 30(5):783-792. doi: 10.1177/1049732319889354. Epub 2019 Dec 13. PMID: 31830860.

We designed both the focus group and the enter and view visits in a manner that was mindful of participants’ time, privacy and wellbeing.

For the focus group, participants were informed beforehand about the purpose of the session, the nature of the questions and their right to withdraw at any time. The hybrid format allowed individuals to join either in person or online, ensuring accessibility and inclusivity. Ground rules were agreed at the outset to create a safe and respectful environment for discussion.

For the enter and views, to minimise disruption to the wards’ operations, we notified the ward manager via email one week before the visit and provided a digital version of the notification leaflet, requesting it be displayed in the wards. Before engaging in the questions, all participants were informed about the purpose of the visit, the nature of the questions and their right to withdraw at any time.

All participants’ identities were kept confidential and data anonymised during collection.

Findings: Experiencing Adult Sickle Cell Care as an Outpatient

To better understand how patients experience adult sickle cell care outside of inpatient wards, we held a focus group with people living with sickle cell disease. Sixteen participants (11 in person, 5 online) explored their experiences of accessing care as out-patients, including support from GPs, outpatient clinics, A&E and other non-ward settings. Participants were encouraged to share both positive and negative experiences, as well as the impact these experiences have had on their health, wellbeing and trust in services.

What participants shared highlighted consistent patterns across different services and over time. While individual experiences varied, the same issues were raised repeatedly by different people. Participants identified six main themes that shape their experience of adult sickle cell care: the transition from paediatric to adult services; disbelief and stigma in emergency settings; unsafe pain management; primary care failures; the burden of self-advocacy and fragmented care; examples of what good care looks like. These findings provide insight into the systemic barriers people face when accessing adult sickle cell care as out-patients.

A difficult transition from paediatric to adult care

All 9 participants in the focus group who discussed the transition from children to adult services described it negatively.

They spoke to us about "*supportive*", "*responsive*", "*holistic*" paediatric care, with staff who listened to children and their families. However, this changed sharply when they moved into adult care. Adult services were described as "*much less understanding*", "*more dismissive*", "*adversarial*" and "*harder to navigate*".

> When I was a child, I had great care for my sickle cell. As I aged out of the children ward, it was chalk and cheese having to constantly battle medical staff to be heard.

Many said this transition was “*poorly managed*” and “*abrupt*”. Adult services expected patients to suddenly manage complex care independently, explain their condition repeatedly and challenge decisions, often with little support. A third of participants in the focus group described this experience as “*distressing*” and three said it was “*traumatic*”.

The transition fundamentally shaped participants' relationship with adult healthcare services. Those who experienced poor transitions developed lasting distrust of healthcare providers and fear of not being believed. This mistrust persisted years later and affected their willingness to seek care when needed. One participant commented that it led to “*a deep lack of trust”* in adult health services that continues to influence their every subsequent interaction with the healthcare system.

Disbelief and stigma in emergency settings

Disbelief about pain was the most consistently raised issue across the focus group, mentioned by 88% of participants**.** This theme was particularly strong when discussing their experience in A&E, although it also arose in other settings including GP surgeries and general hospital wards.

A&E was described as a place where people face “*long waits”*, “*disbelief”* and “*pressure to go home”* rather than receive treatment.

> I go to AE sometimes. If I am having an infection, they should check my blood count and give me blood. Instead of concentrating on these things, they concentrate on being nice to me and sending me home. They tell me to come back if it gets worse. They put more effort to negotiate with me to go home than it would take to actually help and care for me. Most of the time my concerns are not heard. I am not coming from a night club confused and drunk, I am coming from home. Why are you taking so much effort into sending me back home and telling me to come back if it gets worse?

Participants agreed that in A&E they “*are often not believed when [they] explain how much pain [they are in] or describe other symptoms*”. They felt that staff made judgement about pain relief “*often based on how someone looked, rather than what they said”*.

> This is a no-win situation, if you go all in you are seen as aggressive; if not, you are not taken seriously. I had written on my discharge letter that I came in for pain medication but I looked fine. They don’t understand.

> There is no believing patients and not understanding them. They will give you what they think it’s acceptable for them.

Using coping strategies was misinterpreted as evidence of not being in pain. A participant explained that “*listening to music or reading was taken as evidence that [their] pain was not real”*. As a result, 44% of patients told us they felt “*pressured to visibly show distress in order to be taken seriously”*, which they described as “*humiliating*” and “*unsafe”*.

50% of patients also shared that being labelled as “*dramatic*”, “*difficult*”, or as “*seeking drugs”* was common, especially when they asked for stronger pain relief or questioned decisions about their care.

Because of these experiences, many participants said they “*avoid going to A&E unless they have no other choice”.*

Unsafe pain management

100% or participants in the focus group reported problems with pain management, although the specific issues varied by setting. Delays, inconsistency and disregard for individual care plans emerged as interconnected problems that made pain management feel unsafe.

Participants said pain relief is often “*delayed*”, “*inconsistent”*, or “*changed without proper discussion”*.

> This time around when I came [to A&E] the doctor put me on oral tablets. My care plan says injections, but the doctor would give me just tablets.

We heard waiting times vary between 1.5 and 6 hours for the first dose of painkillers in A&E, despite NICE guidelines requiring treatment within 30 minutes.

These delays have direct clinical consequences. When pain is not controlled early, crises escalate, requiring stronger interventions and often leading to hospital admission that might have been preventable with timely treatment.

63% of participants in the focus group told us that care plans were frequently ignored or over-ridden in A&E or during hospital admissions for other reasons, such as surgery. A patient described having their medication reduced following surgery, which led to severe pain crises.

> I had surgery and the pain was bad. I told staff I have sickle cell but they reduced my morphine because it wasn't in their protocol. I asked them not to, but they didn't listen. They reduced it and the next day I was in full blown crisis. Only then did they follow my care plan and increase the dose again. When they reduced it once more, the pain returned. I kept telling them what I needed, but they insisted on sticking to their protocol. They did not understand that surgical pain triggers sickle cell pain. They are not inside my body, but they still wouldn't listen.

Additionally, participants shared that they "*struggled to access repeat prescriptions, especially through GPs*". Because of this, 75% of participants in the focus group said they "*stockpile pain medication when they can, as a way to protect [themselves] during future crises*". They were clear that this is not a safe practice but they felt it was sometimes "*the only option available*" to them.

The fact that three-quarters of the focus group felt compelled to hoard medication speaks of a profound failure in ensuring reliable access to appropriate pain management.

Primary care failures

GP services also emerged as a failure point in sickle cell care. 94% of patients we spoke to raised concerns about their GP's knowledge, support and willingness to prescribe appropriate medication.

Patients told us they "*have had to become experts in sickle cell disease in order to survive within the system"*. They described regularly having to explain basic information about the condition to their GP and correct their mistakes or misunderstandings.

> Things the GP asked me about sickle cell: "Which side of the family does it come from?" and, "Are you married to your cousin"?

These questions reveal not only a lack of knowledge about sickle cell disease but also assumptions that reflect cultural stereotypes rather than a medical understanding of the condition.

As a result, some patients have stopped using their GP for sickle cell care altogether, while others felt forced to use private GPs.

> My son is in sickle care but I just gave up on it. I took him [to the GP] 2 or 3 times. Every time they did not know what they were dealing with. They ask me "was he born with it?" or they tell me, "take him home and just give him paracetamol". The frustration is real.

> There is no point in going to the GP. There is no point in even trying. My GP said they were uncomfortable to prescribe medication, even if the medication was in my discharge letter.

When patients cannot access pain medication through their GP, they are forced to either manage crises at home without adequate pain relief and risking serious complications or attend A&E for medication that should have been available in primary care. This increases pressure on emergency services, disrupts patients' lives and leads to avoidable suffering.

The burden of self-advocacy and fragmented care

All participants described having to constantly advocate for themselves to receive appropriate care. Self-advocacy often happens at times when patients are in severe pain, exhausted or unwell.

Participants in the focus group felt that “*those who are confident, articulate and persistent are more likely to receive appropriate care”*, while others are at risk of being ignored.

> I am confident in advocating for myself. I wander what would be the experience of somebody who is not confident in advocating for themselves.

Access to appropriate care should not depend on patients’ confidence, persistence or ability to articulate themselves. Yet multiple participants acknowledged that those who are less able to advocate for themselves, such as young people, those with additional disabilities or patients in extreme pain, are at greater risk of receiving inadequate care.

Seven participants with multiple health conditions reported a lack of communication between services and professionals. They told us that their care is often fragmented, with different specialists focusing only on their own area, blaming other conditions rather than working together, and leaving patients to bridge the gaps.

> If you have multiple conditions, the specialists do not communicate with each other. Each doctor blames the other condition but they do not work together to figure out what to do. There is a lack of integrated care and it's worse if you are in care in different hospitals for different reasons.

This fragmentation forces patients to become coordinators of their own complex care, often without the medical knowledge or systemic access to do so effectively. The result is delayed treatment, worsening health problems and, in some cases, serious preventable harm.

What good care looks like

Despite many negative experiences, participants were clear that "*good care is possible*". A small number of clinicians were described very positively. These clinicians "*listened without judgement*", "*treated patients as experts in their own bodies*" and "*tailored care to the individual*". They "*communicated clearly*" and "*worked [with patients] to make decisions together*".

> Dr. Dimitri always listened to me, he gave me his email, I would email him and he would respond to the problem. "You are an expert in your condition" he used to say.

> Think about cancer, you have cancer, they give you the drug, here you always have to justify and advocate for yourself. The best doctors listen and ask questions in a nonjudgmental way, they ask curiosity questions, not interrogation questions. They talk through the plan with you, they will help you understand but also allow you to ask questions and discuss options so you can come to a conclusion together.

Patients also told us that offering good support means clinicians must strive to coordinate care across various services. Where this happened, people felt safer, experienced fewer crises and were better able to live their lives beyond their condition.

> The GP helped me contact the hospital so I could go to university and stayed in contact and gave me room to decide what to do care-wise. He was not judgemental: he told me to experience things but in moderation. It was helpful because I was not concerned that my health would hold me back. It was arduous but we got there.

These positive examples describe good care as an individual choice rather than a system design. Patients felt that good clinicians choose to practice differently within systems not designed to support good care. In their eyes, good care happens when individual healthcare professionals made personal commitments to listen, coordinate and trust patients. This suggests that good sickle cell care currently depends on luck—encountering the right clinician—rather than on reliable, system-level standards that all patients can expect to receive.

Overall, our research reveals a pattern of systemic problems in adult sickle cell care for outpatients, rather than isolated failures. Patients are routinely forced to advocate for themselves to compensate for gaps in knowledge, communication and coordination across services. When care works well, it is usually because individual clinicians choose to listen and work collaboratively, not because the system is structured to support this approach. The elements of good care include being believed, having care plans followed, receiving timely pain relief and experiencing coordinated support across services. This should be the baseline standard for all patients, not exceptional experiences dependent on encountering particular clinicians.

The consistency of these themes across patients' ages, genders and different GP practices suggests these are not one-off experiences but entrenched patterns in how sickle cell care is delivered outside specialist inpatient settings.

Findings: Patient experience of sickle cell care at Lloyd Ward

On 10th July 2025, we carried out an Enter and View visit to Lloyd Ward to understand the experience of patients receiving inpatient care for sickle cell disease and to hear directly from ward staff.

During this visit, we spoke with two patients (the only sickle patients on the ward that day) and three members of staff, including a junior sister, a receptionist and the matron covering from the Acute Care Unit (ACU). While this is a small patient sample, the themes raised by these two patients align closely with the issues we identified in our focus group and with historical patterns documented in our 2015 Enter and View report and the 2021 parliamentary review. This strengthens confidence that they reflect broader concerns.

Comparing the findings from this enter and view with our previous work in 2015, we have identified significant positive changes in the ward environment and staff attitude, while pain management, communication, stigma and staffing levels require further improvements.

A place of relative safety and specialist care

In 2015, patients on Lloyd Ward described staff as "*very rude*," "*malicious*" and "*spiteful*”. However, in our last visit, the two patients we spoke to described Lloyd Ward as a more supportive and understanding environment, especially when compared to other parts of the health system, such as A&E, other wards and GP services, which many sickle cell patients find more difficult to navigate.

> The doctors in A&E don’t understand … but I enjoy the staff in this ward. They are the best you’ll find.

One inpatient, who has been admitted to Lloyds ward several times over many years, spoke very positively about the ward and the staff, describing them as “*professional*” and saying that they “*try their best*”. Another patient highlighted that they “*continue to return to Lloyd Ward even after moving out of the area, because [they] feel better understood there*”.

> I feel they value “patient first” care

> Practitioners have grown in empathy

Patients attribute these changes to staff’s improved knowledge of sickle cell, which has contributed to their increased empathy and a more patient-centred approach.

These findings reflect what we heard in the focus group, where participants described a small number of settings and clinicians who provide more compassionate, informed care. Lloyd Ward has the potential to become one of these places. It is important to note that "*better than A&E and GPs*" is a low bar. Patients were describing Lloyd Ward as the best option available to them, not necessarily as providing consistently excellent care. The ward is praised in relative terms, compared to worse experiences elsewhere, rather than being described as uniformly positive in absolute terms.

Listening and understanding

Patients’ experiences of being listened to on Lloyd Ward were mixed and depended on which staff was looking after them, with haematology specialists and senior staff described more positively than nurses or on-call doctors who were not sickle cell specialists.

> I feel that the haematology specialists and more senior staff listen and understand [me]. Nurses and on-call doctors, well, less so.

This echoes a strong theme from the focus group, where people described not being believed or having their concerns dismissed, particularly outside specialist services.

> Accessing good care depends on where you present, who you see and how confident you feel in advocating for yourself. It has little to do with your actual clinical needs.

Staff, by contrast, emphasised listening as a core part of their approach. They spoke about “*knowing patients well*”, “*building relationships over time*”, and “*encouraging patient-led decision-making*”.

> The main thing is to listen to the patient and follow their care plan. There is nothing set in stone and we review to meet patients’ needs.

> We know them, we know their preferences, we have relationships with them, we know who to contact and how to escalate.

The gap between staff and patient perspectives suggests that while listening is valued in principle, patients do not always experience this as consistent or meaningful in practice. For patients, feeling listened to often depends on whether their concerns lead to action and adjustments in their care.

This disconnect may reflect several factors. Staff working at capacity may have less time for the extended, attentive listening that patients need. When stretched, they may unconsciously prioritise efficiency over building relationships with their patients. Additionally, what staff consider listening, such as acknowledging concerns and making notes, may not always match what patients need (having concerns acted upon, feeling believed, seeing care adjusted in response to feedback).

Pain management

Staff told us the ward tries hard to follow individual care plans, use pain pumps and conduct regular assessments. Both patients we spoke to agreed and felt that pain management had “*improved over time*”. This is an improvement compared to our 2015 report, where we heard accounts of patients having to wait hours for pain relief.

Despite this, neither patient described consistently receiving pain relief within 30 minutes. This mirrors national patterns: the 2021 parliamentary inquiry on sickle cell care found that even in specialist haematology settings compliance with the 30-minute standard varies significantly, with some services achieving over 90% compliance while others achieve only 20-30%.

When pain relief was delayed or inconsistent, patients and staff attributed it to system pressures rather than staff indifference. Patients spoke to us about “*staffing pressures*” and “*delays in getting medications prescribed*”. One senior nurse explained that “*when nurses are caring for several patients at once or when prescriptions require approval from doctors who are not based on the ward, delays do happen*”. By staff’s own admission,

> On Lloyd Ward these issues are less severe than in A&E but they have not been fully resolved.

This closely reflects findings from the focus group, where delayed or reduced pain relief was described as a major cause of distress and avoidable crises.

In response to our 2015 report, Homerton hospital implemented pain relief monitoring and made it a key performance indicator tracked monthly. This has led to measurable improvements. However, monitoring alone does not eliminate the underlying systemic barriers of staffing constraints, delays in getting prescriptions authorised and competing demands when multiple patients need complex pain management simultaneously.

Communication and discharge planning

Communication was identified as an area of improvement by both patients and staff. Patients spoke about being *“left unsure about what was happening”*, particularly around discharge. Infrequent updates and unclear plans increased their anxiety and frustration.

I hate being left unsure

Our 2015 report documented significant communication failures, including patients not knowing their consultant's name, lack of clarity about treatment plans and discharge delays where patients waited hours for take-home medication without updates. In our latest visit we found that some aspects of communication have improved. For example, we noted that patient boards now display more information. However, the core problem of patients feeling uncertain and uninformed persists.

Staff recognised communication as a challenge, too, especially during busy periods or when staffing levels are stretched. One staff member specifically told us that *"Communication between staff and patients is an area where improvements could be made"*, adding, *"We are always learning and we know that things can always be improved."*

This aligns with focus group findings, where poor communication and lack of coordination across different parts of the hospital system were described as ongoing problems.

Communication failures can be linked to staffing pressures and the complexity of Lloyd ward**.** Staff explained that during busy periods or when staffing levels are stretched, maintaining clear, regular communication with patients becomes more difficult. On a mixed ward treating sickle cell patients alongside patients with other conditions, coordination across multiple specialties adds complexity. Updates about discharge may depend on input from pharmacy, on-call doctors, social services or community teams, all of which can add to delays and uncertainty.

Stigmatisation of sickle cell patients

Patients' accounts suggest that stigma and assumptions about drug-seeking behaviour have reduced on Lloyd Ward, especially when compared to A&E and primary care but have not been fully eliminated.

One patient told us they felt "*people with sickle cell are sometimes treated unfairly and stereotyped as seeking drugs*".

> They think we just want drugs, like we're addicts.

This echoes strong themes from the focus group, where stigma and disbelief were described as central to participants' experiences.

On Lloyds ward, however, patients told us that “*staff are trying to improve”* and that “*feedback has led to some positive changes”.*

Staff told us that this is the result of a structured and reflective approach to feedback and complaints. Informal feedback, concerns sent to PALS and formal complaints are shared with the ward manager and discussed in team meetings. Staff involved are supported through one-to-one conversations that aim to understand different perspectives, with an emphasis on learning rather than blame. Learning is then shared across the team to support ongoing improvement.

Despite these efforts, the fact that some patients still feel stereotyped as drug-seekers suggests that deeper cultural and structural issues remain unresolved. The 2021 parliamentary inquiry into sickle cell care highlighted that negative attitudes towards people with sickle cell are often rooted in racism, including false beliefs about pain tolerance and opioid use. This suggests that while improved processes and training can make a difference, they may not be sufficient on their own. Addressing stigma fully is likely to require explicit anti-racism work alongside clinical education and service improvement.

Staffing levels

Staff explained that, in principle, staffing levels on Lloyd ward are considered adequate. During the day, the ward is typically staffed by five registered nurses, including a coordinator and three clinical support workers. At night, this reduces to four registered nurses and two clinical support workers, with further reductions at weekends. Bank staff are used to cover sickness and maternity leave when needed. Staffing levels are formally reviewed twice a year using a patient acuity scoring system, with findings reviewed by the Chief Nurse and reported to the Trust Board. Staff told us that this process has previously led to increases in staffing where required.

However, formal adequacy does not always translate into consistent capacity to meet patient needs in practice. High patient acuity, workload pressures and delays in prescribing medication can stretch teams significantly, even when staffing meets formal requirements. Staff told us they feel these pressures the most during busy periods or when several patients require complex pain management at the same time.

Within this context, staff spoke candidly about the emotional and practical challenges of their work. They expressed confidence in their skills and training and pride in the care provided on Lloyd Ward. They described strong teamwork, good relationships with the sickle cell specialist team and a commitment to learning from feedback. However, they also acknowledged that, when teams are working at full capacity, the emotional and practical demands of the role increase significantly.

> Patients can sometimes speak to us in challenging ways… Acts of incivility can have a real impact on us, particularly when we are already under pressure.

It is important to recognise that patients in severe pain, fear or distress may express frustration in ways that staff find difficult. Findings from the focus group help to contextualise this, showing that patients often feel forced to advocate forcefully in order to be believed or receive appropriate care. This can create a cycle in which patients feel they must push hard to be heard, while staff experience this behaviour as incivility, particularly when resources are stretched.

This suggests that while staffing levels on Lloyd Ward are assessed as adequate on paper, the combination of high clinical demand, complex care needs and emotional labour place significant strain on staff. When capacity is limited, this can affect both staff wellbeing and the consistency of patient experience.

Overall, our conversations with staff and patients indicate that Lloyd Ward is managing the consequences of wider system failures. Patients often arrive on the ward already distressed by negative experiences in A&E or primary care. Staff are working hard to provide specialist, compassionate care but are doing so under significant pressure. The gap between patient and staff appears to be less about intent and more about system pressures.

Findings: Patient experience of sickle cell care at the Medical Day Unit (MDU)

We carried out an Enter and View visit to the Medical Day Unit (MDU) on 6 November 2025 to understand how people experience sickle cell care in this setting and to hear directly from staff working in the unit. During this visit, we spoke with 8 patients and 3 staff, including 2 senior nurses and a receptionist. The consistency of accounts shared provides valuable insight into how care is delivered and experienced at the MDU.

The MDU represents a model of care for sickle cell that other settings should aspire to. While every other setting we investigated revealed significant problems (disbelief and delays in A&E; GP services marked by ignorance and refusal to prescribe medication; Lloyd Ward delivering variable care depending on which staff are on duty), patients consistently described the MDU as "*safe*", "*responsive*" and "*trustworthy*".

Access to care

Patients told us they value the predictability and ease of access to the MDU during its operating hours. The ability to phone ahead, attend on the same day and follow a clear process gave them confidence to seek help early. Staff described these arrangements as a way of managing demand while ensuring patients can be assessed and treated safely.

However, both patients and staff were clear about the limits of this model. The MDU treats patients on Monday to Friday between 9 am and 6 pm, with the last admission at 3 pm. After 3 pm during the week and at the weekend patients are directed to A&E. This creates a sharp change in their experience. While the MDU is "*trusted*" and "*responsive*", being pushed back into A&E often means "*facing long waits*", "*dealing with lack of specialist knowledge*" and "*fear of not being believed*". As a result, patients experience inequality in access to appropriate care.

A safe and trusted environment

Patients consistently described the MDU as a "*calm*", "*welcoming*", "*comforting*" and "*reassuring*" place, where staff are "*kind*" and "*always going above and beyond*". 6 out of 8 patients contrasted their positive experience at the MDU with the challenges they faced in A&E, GP services or other hospital settings.

> I am well looked after here and I feel staff here listen to me and believe me. It's nothing like A&E, where they scream prejudice at you.

> My GP hasn't got a clue. I come here and I know I can trust them to look after me properly.

One patient suggested that the MDU **"***should act as a blueprint for other wards***"**, reflecting the high level of trust and confidence patients have in the unit. Patients did not just describe good clinical care but also a sense of psychological safety.

The elimination of the need to "*prove*" pain or "*explain myself*" transforms the patient experience. In the focus group, patients identified the burden of constant self-advocacy as one of the most exhausting and demoralising aspects of living with sickle cell disease. At the MDU, patients arrive and are believed, assessed and treated. This contrasts sharply with A&E, where patients have to show distress to be taken seriously, or with GP surgeries, where patients must argue for prescriptions that are clearly documented in their care plans.

Staff actively cultivate this safe environment, with the intent to "*create a space where patients feel safe to attend early, rather than waiting until their condition deteriorates*". A senior nurse told us,

> We make patients comfortable. We ask them where the pain is and when it started. We offer tea and water. We encourage patients to come here as soon as they feel they need, we tell them not to wait, we know that if they wait and delay coming here they will end up in the ward. When a patient comes here, we never turn them away. We know they can deteriorate within minutes.

A patient told us how this approach shaped how safe and supported they felt when attending the MDU:

> Sometimes it's like going to see an old friend. They know me and remember me. They already know who I am and what I need. I don't have to explain myself or prove that I am in pain. They look at my care plan, listen to me and do the right thing. I feel they take me seriously.

This sense of familiarity is another strong theme from patient accounts about their experience at the MDU. All patients we spoke to told us that "*staff know me*", "*understand my medical history*" and "*take my pain seriously*" from the moment they arrive.

Staff also described this familiarity as "*central to safe care*". They spoke about knowing patients' usual pain patterns, recognising when someone is deteriorating and understanding when a presentation is unusual or more serious than it appears. This knowledge allows staff to move quickly from assessment to action.

Familiarity also creates a virtuous cycle. Because staff know patients, patients trust staff. Because patients trust staff, they attend early when symptoms are still manageable. Because patients attend early, staff can intervene before crises escalate. This prevents deterioration, avoids hospital admissions and reduces the risk of complications, ultimately leading to better health outcomes.

Effective pain management

Patients and staff consistently praised the speed of assessment and pain relief at the MDU. We heard that “*patients are typically assessed and given medication within around 30 minutes*”, with one-to-one observation and rapid escalation if pain is not controlled.

> My pain is taken seriously and managed properly. I have no complaints.

Both patients and staff see timely intervention as the key factor in preventing further deterioration, avoiding hospital admission and reducing the risk of escalation to intensive care. This finding reinforces what we heard in the focus group, where delays in pain relief were described as directly triggering severe crises and hospital admissions.

We understand from staff that this is possible because they have the competency and autonomy to assess and administer pain relief without waiting for authorisation from doctors who may be unavailable. Protocols are clear and consistently followed. One-to-one observation allows staff to monitor response to treatment and escalate quickly if pain is not controlled.

However, the MDU also operates a "three strikes" policy that creates unintended barriers to care. Patients also told us, “*You come [to the MDU] three times and after that you are admitted to the ward*”. We understand from staff that this is “*intended to keep patients safe by recognising when pain is no longer manageable at home*”.

In practice, however, this policy discourages some patients from attending the MDU when they need to. Two patients told us they had chosen to go to A&E instead of the MDU specifically to avoid triggering the three-visit threshold, particularly when admission would disrupt work or caring responsibilities. This means patients are choosing poorer care at A&E over superior care at the MDU to avoid being admitted to hospital. This defeats the purpose of the policy, as patients who delay seeking appropriate care are more likely to deteriorate to the point where admission becomes necessary anyway.

A more flexible approach might involve discussing with patients at the third visit whether admission is appropriate, rather than making it automatic and ensuring patients understand that attending the MDU when needed will not automatically result in admission if they and clinical staff agree that home management remains safe.

Challenges and areas for improvement

Unlike other parts of their care pathway, patients raised no concerns about the quality of clinical care at the MDU. Instead, the main issue identified by both patients and staff was the physical environment. During our visit we observed crowding, limited space and lack of privacy.

These issues were acknowledged by staff, who, when asked what could be improved at the unit, unanimously answered “*space*”.

> We need a bigger space. Today we have 8 sickle cell patients, if more come in we will have to put them in side rooms where staff is not stationed. This makes it challenging for us. When they come in with pain, we need to be able to see them, this is important because we know they can deteriorate quickly.

The current layout also creates a trade-off between safety and dignity. The open-plan design allows staff to continuously observe patients, enabling the rapid response that is essential for safe care. However, this means patients have little privacy during treatment or during conversations with staff about their care. Sensitive discussions happen in a shared space where other patients and visitors can overhear.

Interestingly, though, patients did not frame this as a failure of care but as a practical limitation of an otherwise highly valued service. No patient said the space constraints would prevent them from attending or diminish their trust in the MDU.

Overall, the MDU shows that humane, responsive and effective care is achievable when specialist knowledge, clear protocols and autonomy to act quickly are built into services. Feedback from patients also highlighted that continuity of care and a culture of trust and belief are central to good sickle cell care. The MDU demonstrates that when these elements are in place, patients feel safer, staff experience less conflict and deterioration can often be prevented.

The geography of quality in sickle cell care: how patient experience varies by setting

Patients' experiences of sickle cell care in Hackney vary sharply depending on where care is accessed, rather than clinical need alone. Across our data, care quality consistently aligned with setting: non-specialist services were associated with disbelief and delay, while specialist services offered timely, trusted care. One patient described this as a "*postcode lottery*" within a single ICB.

At one end of this spectrum sit GP services and A&E, where patients reported repeated experiences of being disbelieved, delayed and dismissed. Focus group participants consistently described GPs as lacking basic knowledge of sickle cell disease and being reluctant to prescribe pain medication, even when clearly documented in hospital care plans. Similarly, most participants also shared that in A&E decisions were influenced by how patients appeared rather than by their symptoms, with waits for pain relief ranging from 1.5 to 6 hours, far beyond the 30 minutes NICE guidance. These settings were associated with fear, mistrust and the need for patients to advocate forcefully while in severe pain.

Lloyd Ward sits between specialist and generalist care. Patients described it as more supportive and professional than A&E or primary care and acknowledged the ward has improvements over time, particularly in pain management. However, patient experiences remained inconsistent. Quality of care depended heavily on which staff were present, with haematology specialists perceived as more responsive than non-specialist or on-call staff. Communication, particularly around discharge, remained a source of anxiety.

At the other end of the spectrum is the highly specialised Medical Day Unit (MDU). Here, patient experience was consistently positive. Patients described the MDU as "*calm*", "*welcoming*" and "*safe*", reporting that they were believed immediately, assessed quickly and treated within 30 minutes. Unlike other settings, patients did not raise concerns about clinical care; the only criticisms related to physical space due to overcrowding and a lack of privacy. Several patients explicitly contrasted the MDU with other services, with one suggesting it "*should act as a blueprint for other wards*."

Across settings, we identified five structural factors that explain these differences:

- Specialist knowledge: Concentrated expertise in the MDU meant patients consistently felt understood, while diluted knowledge in generalist settings led to delays and less responsive care.
- Continuity: Stable staff teams in the MDU enabled trust and faster decision-making, whereas one-off encounters elsewhere required patients to repeatedly explain and justify their needs.
- Autonomy: Nurse-led authority to act quickly in the MDU enabled timely pain relief; bureaucratic approval processes elsewhere created delays.
- Culture of trust and belief: The MDU operates from an assumption that patients are credible and experts in their own condition, in contrast to cultures of suspicion in A&E and primary care.
- Consistent protocols: Clear, reliably followed care pathways in the MDU created predictability and trust, while ad-hoc decision-making elsewhere led to worst patient outcomes.

These differences matter. Delayed pain relief increases the risk of crisis escalation, hospital admission and serious complications. Repeated experiences of disbelief and dismissal lead patients to delay seeking care, avoid services altogether or manage pain unsafely at home.

This pattern mirrors national findings from the 2021 parliamentary inquiry into sickle cell care, indicating that the issues identified are systemic rather than local.

The MDU demonstrates that safe, effective and humane care is achievable when services are designed around specialist knowledge, continuity, autonomy and trust. The central challenge is not whether good care is possible but why it remains confined to a small number of settings rather than embedded across the whole pathway.

These findings suggest that improving consistency across points of entry into the care system, particularly GPs and A&E, would make a significant difference to patient experience, safety and wellbeing.

Recommendations

Based on all the evidence collected on sickle cell patients’ experience of care, our 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 A&E

1.1 Review and strengthen standards for how people with sickle cell disease should be treated in A&E

Homerton Hospital should develop and implement clear expectations for how adults with sickle cell disease are received, listened to and supported in A&E, 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.

Rationale: This recommendation responds directly to repeated patient reports of disbelief, dismissal and fear when attending A&E.

1.2 Strengthen awareness of sickle cell care plans and escalation routes in A&E

A&E 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.

Rationale: Patients’ experiences show that inconsistency in recognising and following care plans is a major source of distress and delay in emergency settings.

1.3 Address racism, stigma and bias through explicit reflective practice

The Trust should introduce regular reflective learning sessions for A&E teams focused on:

- 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.

Rationale: Patient insight makes it clear that training alone is insufficient without explicit attention to tackling racism, bias and stigma.

2. Protect, sustain and share learning from the Medical Day Unit (MDU) model

The Trust should actively protect and sustain the MDU, recognising it as a model of good practice in sickle cell care. The Trust should also consider how learning from the MDU's approach to communication, patient autonomy and responsiveness could inform practice in other settings, including A&E and inpatient wards.

Rationale: Patient feedback showed that the MDU model supports humane, responsive and effective care for sickle cell patients.

3. 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 support patients' dignity, comfort and confidentiality and does not undermine their otherwise positive experience.

Rationale: While patients expressed very high confidence in the quality of care provided at the MDU, the main concern raised was the physical environment, particularly crowding and lack of privacy.

Recommendations to Lloyd Ward

1. 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.

Rationale: Patients told us that uncertainty about what was happening contributed to anxiety and frustration, even when staff were trying to help. Clear explanations, regular updates and opportunities for patients to ask questions would help reduce distress and improve trust.

2. Deepen reflective work on racism, stigma and bias

The ward should build on existing reflective practice by continuing 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.

Rationale: While patients recognised that care on Lloyd Ward has improved over time, some still reported feeling stereotyped.

Recommendations to North-East London Integrated Care Board (NEL ICB)

1. Improve access, consistency and confidence in care provided by GPs

1.1 Improve GPs' understanding of sickle cell disease and patient pathways

The ICB should work with GP practices to improve their knowledge and awareness of sickle cell disease, focusing on:

- Understanding patient lived experience of pain and crisis.
- Knowing when and how to follow hospital discharge letters and care plans.
- Recognising when reluctance to prescribe or refer creates avoidable harm.

Rationale: Participants consistently described GP knowledge gaps as a key reason for disengaging from primary care altogether.

1.2 Reduce avoidable reliance to A&E

GP services should be supported to act as a reliable first point of contact for people with sickle cell disease, particularly around repeat prescriptions, referrals and early intervention. Where GPs are unable or unwilling to support patients, this should trigger review and support rather than leaving patients with no option but A&E.

Rationale: The report shows that failures in primary care directly increase pressure on emergency services and worsen patient outcomes.

1.3 Involve sickle cell patients in designing improvements to GP access

People living with sickle cell disease should be involved in shaping GP-level improvements, including how appointments, prescriptions and communication are managed.

Rationale: Improvements supported by lived experience will help rebuild trust and ensure changes reflect real barriers experienced by patients.

2. Improve consistency across points of entry into the system

2.1 Reduce variation in experience based on where patients present

The Trust and ICB should work together to reduce the sharp drop-off in patient experience between specialist and non-specialist settings. This includes:

- Learning from what works well in specialist services (such as the MDU).
- Applying those principles to first-contact services like A&E and GPs.

Rationale: Patients' experiences suggest that care is too often shaped by setting rather than need, leading to avoidable harm and distress.

3. Improve coordination and support during the transition from paediatric to adult sickle cell care

To improve patient experience and reduce long-term distrust, the Trust should review how transition is currently managed and consider ways to ensure:

- clearer communication about what adult services involve and how care will change
- better coordination between paediatric and adult teams, so patients do not feel they are "starting again"
- additional support during early adult care, recognising that patients are expected to manage more complex systems at a vulnerable stage of life

Rationale: Participants in the focus group consistently described this transition as poorly managed, distressing and, in some cases, traumatic, with a sharp decline in feeling listened to and supported once adult care began. Improving this transition would help build trust earlier, reduce the burden of self-advocacy and support more positive engagement with adult services over time.

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