

Title of Report	Community Voice: Sickle Cell Services
For Consideration By	Health and Wellbeing Board
Meeting Date	21 Jan 2026
Classification	Public
<u>Ward(s) Affected</u>	All
Report Author	Sara Morosinotto Enter and View Manager, Healthwatch Hackney

Is this report for:

<input checked="" type="checkbox"/>	Information to note	<input type="checkbox"/>	For actions to be allocated
<input type="checkbox"/>	For Discussion & input	<input type="checkbox"/>	For escalation (if issue is outwith Remit of HWB)
<input type="checkbox"/>	Decision		

Why is the report being brought to the board? ***In three bullet points or less***

- To highlight persistent inequalities in sickle cell patient experience across the local care pathway, particularly in A&E and primary care, and their impact on sickle cell patients.
- To share evidence of what works, drawing on the Medical Day Unit and specialist care as models of good practice that reduce harm and escalation.
- To invite system-level leadership and coordination for improvements, as the issues identified cut across NHS providers, primary care, commissioning and transition between services.

Provide a succinct summary of the issue here:

- People living with sickle cell disease in Hackney experience highly variable care depending on where they access services, with poorer experiences in A&E and primary care compared to specialist settings.
- Disbelief, stigma, delayed pain relief and poor communication remain common

outside specialist services, affecting patient safety, trust and wellbeing.

- As a result, patients often delay seeking care, avoid services, or self-manage in unsafe ways, increasing the risk of worsening their condition and of hospital admission.

Has the report been considered at any other committee meeting of the Council or other stakeholders?

- Alesia Parker, Matron, Lloyd Ward
- Dr. B. Chatterjee, Consultant Haematologist, Homerton
- Basirat Sadiq, CEO, Homerton
- Breeda McManus, Chief Nurse, Homerton
- Giovanni Cappello, MDU matron
- Natasha Lewis, Lead Nurse for sickle cell and thalassaemia functions
- Oleander Agbetu, Solace
- Thomas Clarke and team, ICB Primary Care
- Yetunde Oke, Ward Manager, Lloyd Ward

1. Background

- 1.1. In 2015, Healthwatch Hackney [documented](#) serious problems in sickle cell care at Homerton Hospital including poor staff attitudes, inadequate pain relief and cleanliness concerns. This 2025 follow-up study aims to understand adult sickle cell patient experience across different parts of the care pathway.
- 1.2. Evidence was gathered through a focus group with 16 people living with sickle cell disease, and Enter and View visits to Lloyd Ward and the Medical Day Unit at Homerton Hospital, where we spoke with 10 patients and 6 staff.
- 1.3. The research aimed to identify systemic patterns, highlight good practice, and inform practical, experience-led recommendations. The research was informed by the 2021 parliamentary inquiry "[No One's Listening](#)," which documented national failures in sickle cell care contributing to preventable deaths.

2. Current position

- 2.1. Improvements have been made over time, particularly in specialist settings, but patient experience remains uneven and overly dependent on point of entry into the system.
- 2.2. Specialist services (particularly the Medical Day Unit, and to a lesser extent Lloyd Ward) provide safer, more trusted and more responsive care. The Medical Day Unit demonstrates excellence through specialist knowledge, continuity of care, nurse autonomy and a culture of trust.

- 2.3. Lloyd Ward has significantly improved since 2015—staff attitudes transformed from "rude" and "spiteful" to "professional," cleanliness addressed, and pain relief monitoring implemented. However, quality of care depends on who is on duty rather than on patient needs.
- 2.4. Non-specialist settings (A&E and GP services) are consistently associated with negative experiences, including disbelief, inconsistent pain management and poor coordination. Racism and stigma persist.
- 2.5. The transition from paediatric to adult services is poorly managed and described by all participants as "traumatic."

3. Key facts and/or data

- 3.1. 88% of patients in the focus group reported being disbelieved about their pain in A&E
- 3.2. 50% of the participants in the focus group described being labelled as drug-seeking when requesting appropriate pain relief in A&E.
- 3.3. 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
- 3.4. 81% of patients shared that their GP refuses to prescribe pain medication despite clear hospital documentation.
- 3.5. 75% of patients stockpile medication because they cannot reliably access prescriptions, despite knowing that this practice is not safe.
- 3.6. 100% of patients on the day of our visit described the MDU as safe, welcoming and trustworthy.

4. Conclusions

- 4.1. Variations in patient experience are driven less by individual staff intent and more by system design, culture and consistency across services.
- 4.2. Where good care happened, we observed five structural enabling factors:
 - specialist knowledge
 - continuity of care
 - staff autonomy to act quickly
 - culture of trust and belief
 - consistent protocols
- 4.3. These elements are absent in A&E and primary care, causing harm. The critical question is not whether good care is possible but why it remains confined to one setting (MDU).
- 4.4. Addressing disparities at key entry points (A&E and primary care) and strengthening transitions and joined-up working would significantly improve outcomes for people living with sickle cell disease.

5. Recommendations

Recommendations to Homerton Hospital NHS Foundation Trust

1. Improve patient experience and trust in A&E
 - a. Review and strengthen standards for how people with sickle cell disease should be treated in A&E
 - b. Strengthen awareness of sickle cell care plans and escalation routes in A&E
 - c. Address racism, stigma and bias through explicit reflective practice
2. Protect, sustain and share learning from the Medical Day Unit (MDU)
3. Address the practical constraints of space and privacy in the MDU

Recommendations to Lloyd Ward

1. Strengthen communication with patients throughout their stay
2. Deepen reflective practice on racism, stigma and bias

Recommendations to NEL ICB

1. Improve access, consistency and confidence in the care provided by GPs
 - a. Improve GPs understandings of sickle cell disease and patient pathways
 - b. Reduce avoidable reliance on A&E
 - c. Involve sickle cell patients in designing improvements to GP access
2. Improve consistency across points of entry into the system
 - a. Reduce variation in experience based on where patients present
3. Improve coordination and support during the transition from paediatric to adult sickle cell care

6. Policy Context

Please detail which, if any, of the Health & Wellbeing Strategy priorities this report relates to?

<input type="checkbox"/>	Improving mental health
<input type="checkbox"/>	Increasing social connection
<input type="checkbox"/>	Supporting greater financial security
<input type="checkbox"/>	All of the above

Please detail which, if any, of the Health & Wellbeing Strategy 'Ways of Working' this report relates to?

<input type="checkbox"/>	Strengthening our communities
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<input type="checkbox"/>	Creating, supporting and working with volunteer and peer roles
<input checked="" type="checkbox"/>	Collaborations and partnerships: including at a neighbourhood level
<input checked="" type="checkbox"/>	Making the best of community resources
<input type="checkbox"/>	All of the above

7. Equality Impact Assessment (EIA)

Has an EIA been conducted for this work?

<input type="checkbox"/>	Yes
<input checked="" type="checkbox"/>	No

8. Consultation

Has public, service user, patient feedback/consultation informed the recommendations of this report?

<input checked="" type="checkbox"/>	Yes
<input type="checkbox"/>	No

Have the relevant members/ organisations and officers been consulted on the recommendations in this report?

<input checked="" type="checkbox"/>	Yes
<input type="checkbox"/>	No

9. Risk Assessment

Risk area	Description of risk	Likelihood	Impact	Mitigation / controls in place	Residual risk
Participant distress	Participants, particularly those living with sickle cell disease, may have been unwell, in pain or distressed when sharing experiences of care.	Medium	Medium	Participation was voluntary; participants could pause or withdraw at any time. Researchers used sensitive, trauma-aware approaches and adapted engagement based on participants' wellbeing.	Low
Confidentiality and anonymity	Risk of individuals being identified through quotes or detailed accounts.	Low	Medium	No personal identifiers collected or reported. Quotes anonymised. Findings presented thematically rather than as individual case studies.	Low
Safeguarding	Potential disclosure of unsafe care or harm during data collection.	Low	High	Researchers were alert to safeguarding concerns and informed about correct procedure to follow.	Low
Staff morale and relationships	Findings may be perceived as criticism of staff.	Medium	Medium	Staff perspectives included alongside patient accounts. Findings framed within system pressures rather than individual blame. Emphasis	Low

				placed on learning and improvement.	
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10. Sustainability

- 10.1. This research is sustainable in both its approach and its implications.
- 10.2. The work was delivered using existing Healthwatch processes, including focus groups and Enter and View activity, requiring no additional long-term resources or infrastructure. It draws on lived experience and frontline insight that can continue to inform service improvement beyond the life of this project.
- 10.3. The findings support system sustainability by highlighting where current care pathways lead to avoidable escalation, including delayed presentations, increased A&E use and preventable inpatient admissions. By identifying features of care that enable early intervention, trust and continuity, the report points to opportunities to reduce pressure on acute services over time.
- 10.4. Implementing the recommendations would support more efficient use of resources by:
- encouraging earlier, appropriate access to care,
 - reducing avoidable crises and admissions,
 - improving patient trust and engagement with services.
- 10.5. Overall, the research promotes a more sustainable model of care by supporting consistency, prevention and better use of existing specialist expertise, rather than reliance on high-cost emergency and inpatient care.

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Appendices	<ul style="list-style-type: none"> ● Report: Patient Voices: sickle cell services in Hackney - what has changed 10 years on? ● Risk Report in Full