

# Patient Voices: Sickle Cell Care in Hackney

*What Has Changed 10 Years On?*

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Scrutiny Meeting | Hackney | 2026

# WHAT WE DID

A follow-up to Healthwatch Hackney's 2015 report on sickle cell care

## Focus Group

16 participants with lived experience of sickle cell disease  
(June 2025)

## Lloyd Ward

Enter & View visit — 2 patients,  
3 staff  
(July 2025)

## Medical Day Unit

Enter & View visit — 8 patients,  
3 staff  
(November 2025)

Findings compared with our 2015 report and the 2021 parliamentary inquiry 'No One's Listening'

# THE POSTCODE LOTTERY OF SICKLE CELL CARE

*Care quality is determined by WHERE patients present, not by their clinical need.*

## A&E & GP Services

Disbelief · Delay · Dismissal

## Lloyd Ward

Improved · Inconsistent

## Medical Day Unit

Trusted · Responsive · Excellent

*"It's a postcode lottery within the system"*

# WHERE CARE NEEDS IMPROVING

## EMERGENCY CARE (A&E)

- 88% of patients disbelieved about their pain
- Decisions based on how patients look, not their symptoms
- Pain relief waits of 1.5 to 6 hours — far exceeding 30-minute NICE standard
- 50% labelled as 'drug-seeking' when asking for appropriate pain relief
- Care plans ignored or overridden
- Many patients avoid A&E unless they have no other choice

## PRIMARY CARE (GPs)

- 94% of patients raised concerns about GP knowledge of sickle cell
- GPs asked if patients 'were born with it' or 'married to their cousin' — ignorance and cultural stereotyping
- 81% of patients said their GP refuses to prescribe pain medication despite clear hospital documentation
- 75% stockpile medication — because no reliable access

# WHERE CARE WORKS: THE MDU AS A BLUEPRINT

*100% of MDU patients described care as safe, welcoming and trustworthy.  
Patients were believed immediately, assessed and treated within 30 minutes.*

1

## Specialist Knowledge

Dedicated team deeply understands sickle cell — patients feel heard and treated correctly

2

## Continuity of Care

Low staff turnover builds familiarity and trust, enabling faster decisions

3

## Staff empowered to act

Trained nurses can administer pain relief without waiting for doctor authorisation

4

## Culture of Trust

Patients treated as credible experts in their own condition — no need to prove pain

5

## Clear Protocols

Consistent care pathways give patients predictability, security and confidence

# LLOYD WARD: PROGRESS, BUT GAPS REMAIN

## 2015

Staff described as "rude, malicious and spiteful"

Cleanliness concerns

Inadequate access to pain relief

Patients felt disbelieved and dismissed

## 2025

Staff described as "professional, trying their best"

Cleanliness addressed

Pain monitoring implemented but neither patient received pain relief within 30-min NICE guidelines

Quality still depends on which staff are on duty; stigma reduced but not eliminated; racism and drug-seeking assumptions persist

# TWO SYSTEMIC ISSUES

## RACISM & STIGMA

**50%**

of focus group participants described being labelled as drug-seeking when requesting appropriate pain relief.

The 2021 parliamentary inquiry found these patterns are rooted in racism — including false beliefs that Black people have higher pain thresholds or are drug-seekers.

Our findings mirror this nationally documented pattern. Training alone is not enough; explicit anti-racism work is needed.

## THE TRANSITION CRISIS

All **9 of 9** participants who discussed the paediatric-to-adult transition described it negatively.

Adult services described as 'more dismissive', 'adversarial' and 'harder to navigate'. The damage to trust persists for years and affects engagement with all healthcare going forward.

# RECOMMENDATIONS

## HOMERTON HOSPITAL

- Improve A&E: strengthen standards, follow care plans, tackle racism
- Protect the MDU model and share its learning across other settings
- Address crowding and lack of privacy in the MDU

## LLOYD WARD

- Improve communication around delays and discharge planning
- Deepen reflective work on stigma, bias and unconscious racism

## NEL INTEGRATED CARE BOARD

- Upskill GPs: sickle cell knowledge, prescribing and care plans
- Reduce avoidable A&E dependency by fixing primary care failures
- Involve patients in designing GP service improvements
- Improve paediatric-to-adult transition with structured coordination