Listening to and Supporting Sickle Cell and Thalassaemia Communities: SCAT Centre Insights

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healthwatch Sandwell

Engaging Communities Solutions

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Introduction

This report has been written by Healthwatch Sandwell, the independent champion for individuals who use health and social care services. HWS role is to gather and represent the experiences of patients, carers, and the public to ensure their voices improve the planning and delivery of local care.
This report focuses on the new Sickle Cell and Thalassaemia Centre (SCAT) at the Midland Metropolitan University Hospital. Our project stated with an initial survey designed in collaboration with Oscar Sandwell, the leading local community organisation for Sickle Cell and Thalassemia support. This was followed by visits and discussions to obtain early feedback from patients, families and staff on this significant service transition.

The Midland Metropolitan University Hospital is a major new NHS hospital in the Sandwell area, constructed to consolidate acute hospital services for the area. The hospital was intended to provide better care environments, the latest technology, and a concentration of specialist services in one place. The relocation of the regional SCAT centre to this hospital was a key component of this consolidation and aimed to deliver a better experience for patients with complex long-term conditions.

About the SCAT Centre

The SCAT centre is a new specialist unit for adults with Sickle Cell Disease and Thalassaemia. It relocated to the new Midland Metropolitan University Hospital from its former location at Birmingham City Hospital. It is a day unit where patients can come for assistance, including help during a pain crisis, frequent blood transfusions, and clinic checkups. It was established since our community has a significant demand for this kind of specialised care.

The Centre's Role and the Conditions It Treats

The facility provides care for two main lifelong blood conditions:

- **Sickle Cell Disease:** This condition requires immediate medical attention and can result in severe pain episodes, or crises.
- **Thalassaemia:** This condition frequently requires monitoring and frequent blood transfusions.

In the West Midlands, there are currently around 1,336 people living with a sickle cell disorder and about 432 people with thalassaemia and other rare inherited anaemias, which shows how many patients rely on this specialist service across the region.

The centre is also the major hub for the West Midlands Adult Haemoglobinopathy Network, which currently looks after nearly 1,800 adults and children with Sickle Cell disease, Thalassaemia and other rare inherited anaemias across 19 NHS trusts. This means it works closely with other local hospitals to organise specialised care for these conditions across the whole region. As a result, it is a highly significant service for a large number of people. Birmingham is a young and ethnically diverse area with high levels of deprivation, which increases the need for specialist haemoglobinopathy services like this centre.

Why We Did This Work

We wanted to understand people's early experiences of this important service following its move to the Midland Metropolitan University Hospital. Our aim is to share what is working well and what could be better, to help the service improve as it settles into the new hospital.

Methodology

To best learn the real experiences of people who use Sickle Cell and Thalassaemia Centre (SCAT), a mixed approach was used to listen and learn. All the experiences were anonymous. Our aim was to get the complete picture of the patient experience, capturing what works effectively in the new centre and where challenges are emerging. By combining surveys, face-to-face conversations, and wider discussions to identify the most important issues to address.

The responses were gathered through three main approaches:

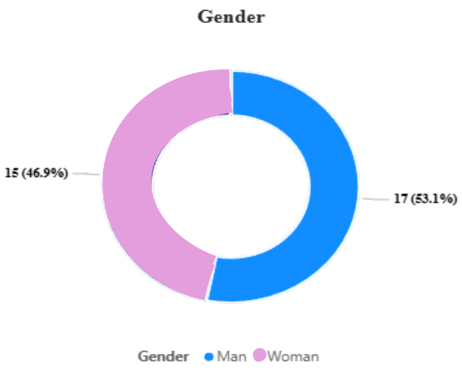
- Patient experience survey
- Visits to the Scat Centre
- Sickle Cell and Thalassaemia Regional Meeting

Across these methods, we focused on understanding patient and carer experiences since the centre's move from Birmingham City Hospital to the Midland Met (MMUH). Key areas of inquiry included:

- What has it been like to receive care at the SCAT centre at MMUH?
- How are the treatment and the support from staff?

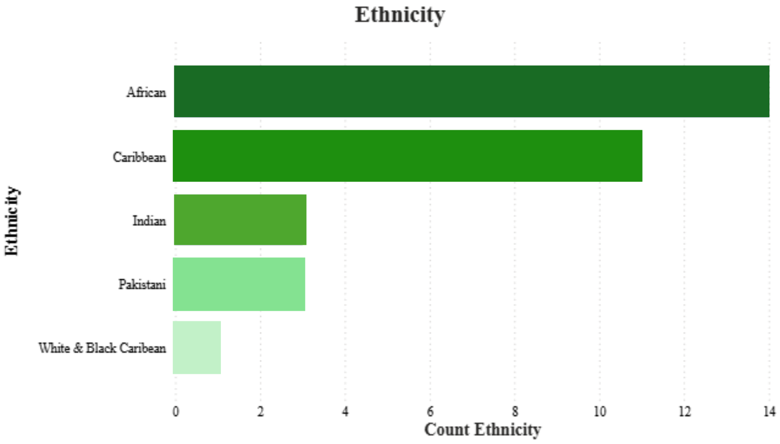
- What is their journey to the centre like, and have there been any challenges getting there?
- How does the SCAT centre at MMUH compare to the old one at Birmingham City Hospital?
- Are there any new or ongoing difficulties in managing their Sickle Cell or Thalassaemia at this location?

Participants Profile



- Woman - 15
- Man - 17

- 18 to 24 – 4
- 25 to 49 - 26
- 50 to 64 - 2



- African - 14
- Caribbean – 11
- Indian - 3
- Pakistani – 3
- White & Black Caribbean - 1

What Participants Told Us

Feedback received from patients highlighted different experiences that existed at the new SCAT centre. Responses were mainly classified as positive, mixed, and negative experiences. While patients were overall very satisfied with their experience, others found it very challenging.

What Works Well

The quality of care at SCAT was well praised by patients. An important factor noted throughout our engagement was having specialist haematology consultants at SCAT, as patients felt it was beneficial to have access to medical expertise in their specific conditions. The standard of nursing care was often praised as caring, attentive, and skilled.

> I came this morning at the SCAT Centre, and it has been an okay experience so far as I feel like the doctors and nurses are specialised in SCD.

> My experience was very positive; I came here for pain management and nurses are friendly and caring. No improvement needed.

> My experience overall has been okay. The department is specialised and quite different from inpatient ward such as haematology. I usually come to SCAT for pain management.

> I used to go to Birmingham City Hospital for blood transfusion, my experience was okay overall, however, it was very outdated.

> I went to the Emergency department at Birmingham City Hospital due to a crisis, I stayed in bed all day waiting to be seen, the place was quite busy and unstructured.

> My experience at Birmingham City Hospital was around 10–12 years ago, and I found the transition from A&E to the ward very challenging. There were times when I had to wait 6 to 7 hours while in significant pain.

The new department at Midland Metropolitan University Hospital was well praised by patients, as it was described as modern, and spacious, which was a big improvement from the older facilities at Birmingham City Hospital.

Main Issues and Challenges

Despite these strengths, various frequent concerns were identified:

Patients reported a lack of follow-up care after treatment.

> In terms of after care, they do not check that much, unless a patient had a blood transfusion recently, however, when I used to go to Birmingham City Hospital, they used to make check in phone calls.

> Aftercare is lacking I feel like it would be good to have follow-ups, however, there are a lot of patients with SCD so it would be practically difficult.

> Allowing direct contact with the nurses would be helpful, but whenever I have a query, I am told to call back after 4pm. When I do call, I often feel rushed and asked to contact them again the following day because the centre closes shortly after 4pm.

Lack of staff in certain occasions and limited beds available for pain management in the day unit.

> A young lady told HWS that she came to the SCAT Centre for a pain management and prescriptions. When she first arrived at the SCAT Centre, she felt like the welcoming receptionist seems to not be interested in what she was saying as when she was waiting, she did not know what she was waiting for however, she thought she was treated like that because they were busy. They did not do the pain management because they did not have the staff for it.

> The service is poor due to lack staff, not enough space for service patients, lack of communication and information.

> Whenever I have a crisis I come here, however, there are only 4 beds available, so I had to wait sometimes.

Restricted visiting time

> I do not agree with the limited visiting times. My sister came to visit at around 11:45 am, but she was informed that she would need to leave and return at 4 pm, which was the next visiting time.

Lift breakdowns made it difficult for some patients in crisis to access the department.

> Few weeks ago, I was having a crisis, so I came to SCAT, however, the lift was not working properly, and it was difficult to manage the pain while waiting for it.

Lack of specialised staff in A&E

> I would like more trained nurses to be available in A&E - I know there are a few but not available when attending A&E but despite the few exceptions of ignorance thinking we are seeking drugs it is the staff that work tirelessly to ensure we receive our medication on time.

> I previously came to A&E because I was in pain, I asked 3 times for painkillers however, they ignored him and I ended up being discharged when they prescribed the pain killers.

Other concerns identified included

- Patients travelling from outside the Black Country face long waits for pain management.
- More investment is required to satisfy the need for blood transfusions.
- Pain management in the community is poor.
- Some patients' hospital records do not clearly flag their Sickle Cell or Thalassaemia diagnosis.

Case study

Samuel's Story

A patient with Sickle Cell Disease shared their experience of being admitted to hospital during an acute crisis. They told Healthwatch Sandwell that the delays and poor communication they experienced added significantly to their distress.

Sunday

Admission Through A&E

He was admitted through A&E on a Sunday in severe pain. He felt the A&E nurse and doctor were slow to respond and deliberately delaying their medication. Once admitted, he had to repeat information about their medication needs multiple times. A doctor took them into a side room for further questions but confirmed no medication would be given there.

The patient waited over 40 minutes without pain relief, despite repeated requests. *"I ended up crying because of how painful it was,"* he said. *"I hadn't had any medication since 4am that morning. I finally received it around 11:20am, still in A&E."*

Delay in Finding a Bed

Despite visible empty beds, he waited over 45 minutes to be moved onto a ward bed. No explanation was given for the delay. *"How long does it take to clean a bed and room? Rubbish service, honestly,"* he told us. By the time they were settled, their legs had become stiff and swollen, and their mobility had worsened.

Transfer to AMU

After more than five hours in A&E, the patient was moved to AMU Bay 26. He noted that the AMU nurses provided more support in 20 minutes than he had received all day in A&E.

Arrival on the Usual Ward

Later, he was transferred to B6, their usual ward. However, the welcome from staff there was described as cold and disorganised, with no record of their arrival. Once staff confirmed his details, care improved temporarily.

Sunday Evening on B6

On B6, medication was given on time initially, and he felt their pain easing. However, this did not last. His legs continued to swell, and although the burning sensation reduced, the pain became more aggressive. *"Before, I could walk in pain because it was so little, but in* *the ward it increased. I don't know what happened,"* he said. He reported this to staff and received medication.

Tuesday

Concerns Ignored

By Tuesday, his left leg had become increasingly swollen and immobile. He repeatedly asked nurses to call a doctor to examine it. Despite assurances that the doctor had been informed, no doctor attended that afternoon.

"I told the nurse multiple times, and he told me he had told the doctor, that they knew, and they were down the hallway. The doctor never came."

When the night shift began, he was told the doctor had left for the day. *"That meant the doctor was ignoring me and my case. No one can say they forgot, I kept telling the nurse I needed to speak to them. I kept saying I needed my left leg checked."*

Wednesday Morning

Further Delays

On Wednesday morning, he experienced another significant delay in receiving pain relief. He had been asking for medication since 7am but did not receive it until after 9am.

"The nurse told me I hadn't been waiting for meds since 7. I couldn't respond because I was in serious pain. She eventually gave me a subcutaneous morphine injection, which calmed my leg down."

Finally Reviewed by a Doctor

Later that day, a doctor examined his legs, confirming they were tender and swollen. An X-ray and possible MRI were scheduled.

Difficulties with Cannulation

He also described a difficult experience with a nurse who attempted multiple cannula insertions despite being told no veins were suitable.

"She pricked me four times instead of two, once in my right elbow joint, once in my hand after I'd told her there were no veins there, and twice in one go on my wrist. I watched her put it in, pull it out, and put it back in another vein. The worst, honestly."

Conclusion

The first year of the SCAT centre at Midland Metropolitan University Hospital has seen both achievements and challenges. Patients have appreciated the new surroundings and the expertise of the specialist team. The walk-in service for pain crises remains an integral part of the service. However, our engagement has also identified various areas where improvements would make a positive difference to patients, particularly around follow-up support and hospital-wide awareness of sickle cell and thalassaemia. Improving these areas would help to build on the strengths of the centre and improve the patient experience. We hope this report supports the centre in its ongoing work to provide high-quality care to the sickle cell and thalassaemia community.

Recommendations

- **Improve Follow-up Care:** Improve a follow-up phone call system after treatment. Patients have stated that this occurred more at the old SCAT centre and that they are missing this service. Also make it easier for patients to contact nurses with questions without being rushed or passed around.
- **Increase staff and beds:** Ensure there are enough staff, so appointments are not cancelled. Also, ensure that there are enough beds in the day unit so that patients in crisis are not left waiting. More investment is also needed for blood transfusions to meet demand.
- **Train A&E Staff on Sickle Cell and Thalassemia:** Ensure A&E staff receive appropriate training to recognise and respond to sickle cell crises promptly. Patients reported being ignored or discharged without adequate pain relief.
- **Extend Visiting Hours**: Review and extend visiting hours to allow families and carers more flexibility to support patients.
- **Ensure Reliable Lift Access:** Put contingency plans in place for lift breakdowns, so patients arriving in crisis can reach the department without delay or difficulty.
- **Improve Support for Patients from Outside the Area:** Review the pathway for patients travelling from outside the Black Country to ensure they receive timely pain relief and are not disadvantaged by their location.
- **Accurately Record Sickle Cell and Thalassaemia in Patient Diagnoses:** It is essential for patient records to have the correct information regarding Sickle Cell or Thalassaemia diagnoses. Clear documentation ensures staff are aware of the patient's condition and can provide timely and appropriate care.

Thank you

We would like to thank Oscar Sandwell for sharing the survey with their community and helping to ensure patient voices were heard. We are also grateful to the SCAT centre for facilitating our visits and supporting this engagement. Most of all, we thank all the patients who took the time to share their experiences with us.

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