

IMPACT REPORT

Sickle Cell Campaign

For generations, people living with sickle cell disease have endured not only physical pain but the deeper pain of disbelief of not being seen, not being heard, and not being designed for.





Natalie Scarlett

Executive Director, The Black Heritage Support Service (BHSS)

At BHSS, we believe visibility is the first step toward equity. The *My Pain Is Real: Designing for Equity* campaign was not created to raise awareness in the traditional sense; it was created to provoke reflection within the health system; to question why Black patients continue to experience inequitable care, delayed treatment, and systemic neglect.

Supported by the **Paul Hamlyn Foundation** and co-designed with sickle cell patients, our campaign used large-scale billboards across Birmingham and London to challenge how healthcare design excludes those most affected. Each message :

“My Pain Is Real,” “Design with Me in Mind,” and “Don’t Restrict Access” , was a public demand for empathy, accountability, and reform.

The campaign also launched a **digital toolkit**, offering practical guidance for both healthcare professionals and patients. This resource helps clinicians adopt inclusive design principles and empowers patients with the knowledge and language to advocate for their rights.

This work is part of BHSS’s wider movement: to reshape how systems are built and who they are built for.

We thank our Advisory Committee, funders, creative partners, and the individuals living with sickle cell who bravely shared their experiences.

Our mission remains clear: design equity into the system, not as an afterthought, but as the foundation of care.



Executive Summary

The **Sickle Cell Awareness Campaign**, led by the **Black Heritage Support Service (BHSS)** and commissioned by the **Paul Hamlyn Foundation**, was a national creative advocacy project focused on the intersection of **design, race, and health equity**.

Launched in 2025, the campaign used powerful public imagery and digital education tools to challenge institutional neglect in the treatment of sickle cell disease.

It was co-designed with sickle cell patients and endorsed by healthcare professionals.



Campaign Objectives

- Highlight systemic bias and poor healthcare design affecting sickle cell patients.
- Educate healthcare professionals through an inclusive design and rights-based toolkit.
- Increase public understanding of sickle cell and the importance of equitable treatment.
- Build bridges between patients, clinicians, and designers through digital advocacy.

Delivery Model

- **Billboards:** Deployed across Birmingham and London with the messages
- “My Pain Is Real,” “Design with Me in Mind,” and “Don’t Restrict Access.”
- **Digital Toolkit:** Accessible via QR code, providing resources for both professionals and patients.
- **Advocacy Integration:** Linked directly to BHSS’s training programmes for health and community advocates

Executive Summary

Measuring Impact

Measuring billboard engagement presents recognised challenges. National data shows that only **1% of viewers typically scan QR codes**, and **CampaignLab (2024)** found an average **7.7% scan rate** for community-based signage.

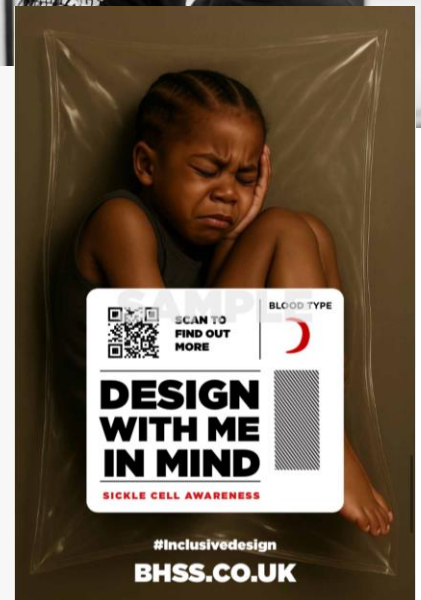
BHSS recorded scans, but due to unknown footfall and restrictions due to driving conditions, we treated this as a **support metric**, not a headline KPI.

Instead, success was measured through **qualitative impact**, the emotional and cognitive engagement of both patients and professionals. Feedback from participants revealed deep resonance with the campaign's imagery and message, affirming its success as a catalyst for empathy and reflection.

"These images really demonstrate the reality of what a sickle cell crisis feels like. If people are able to see this, they might finally understand our pain."

— Sickle Cell Patient

The campaign's wider impact extended beyond awareness, it informed BHSS's **advocacy training curriculum**, strengthening cultural competency modules for professionals and community advocates alike.



About the Campaign



The My Pain Is Real: Designing for Equity campaign began as a creative response to an enduring injustice: that the lived experience of sickle cell patients is often diminished or dismissed within the healthcare system.

Developed through **co-design workshops** with patients and clinicians, the campaign sought to reclaim narrative power, making visible the physical and emotional reality of sickle cell crises, and urging the healthcare system to respond with dignity and care.



Creative Concept and Visual Identity



The billboards were designed by **Phillipe Genus**, using AI and composition to communicate tension, fatigue, and resilience.

Each image reflected both the invisibility of pain and the urgency of recognition. The central figure appearing constricted, anxious, and breathless, visually represented the dual pressure of illness and disbelief.

Taglines such as **“My Pain Is Real”** and **“Design with Me in Mind”** became rallying calls for systemic reform. The campaign used bold images contrasted with red ribbons, evoking emergency and immediacy.

Digital Toolkit



The accompanying toolkit offered accessible, practical guidance for:

Healthcare Professionals: Inclusive design checklists, anti-bias awareness, and pain management protocols.

Patients: Scripts for clinical advocacy, rights under the Equality Act and NHS Constitution, and self-management resources.

Designers and Innovators: Principles for building equitable digital and physical healthcare tools.

This toolkit remains available through the BHSS website and continues to inform local training programmes.

Feedback from the Community



“”

The man in the middle looks tight and stressed, uncomfortable that's how I feel before a crisis.

— Sickle Cell Patient

“”

These images show how it feels to miss out on life, parties, birthdays, because of pain.

— Young Person with Sickle Cell

“”

Doctors need to listen more, especially in adult care. They need to respond fast when pain hits.

— Adult Patient

“”

I think this should be part of our training. We can't know every condition, but we can understand people.

— NHS Professional

The campaign revealed the deep emotional and cultural need for visibility and the urgent requirement for healthcare systems to **design for equity, not uniformity.**



Creative Strategy and Design Approach

Conceptual Framework



The creative direction for My Pain Is Real: Designing for Equity was rooted in one clear question:

What does pain look like when no one believes it?

BHSS worked with **Phillipe Genus**, a Caribbean designer specialising in social-impact communication, to translate lived experience into visual form.

Rather than relying on clinical imagery, the campaign used **emotion as evidence** showing the psychological and physical strain of living with sickle cell, and the emotional toll of systemic disbelief.

The team co-designed every visual with patients and community members, ensuring authenticity and cultural accuracy.

Tone and Messaging



The three core messages were intentionally simple but uncompromising:



“My Pain Is Real”

A declaration of truth in a system that often doubts Black suffering.



“Design with Me in Mind”

A call to healthcare architects, policymakers, and designers to include marginalised voices at the drawing board.



“Don't Restrict Access”

A reminder that inequitable design, whether physical or digital, directly limits access to care.

Each message was accompanied by a QR code leading to the **BHSS Digital Toolkit**, linking public awareness to practical solutions.

Design Choices



- **Imagery:** High-contrast portraits symbolising restriction and resilience.
- **Typography:** Bold sans-serif in red and white— evoking emergency and urgency.
- **Placement:** Billboards in high-traffic, diverse areas of Birmingham and London to ensure maximum visibility.
- **Accessibility:** All visuals met contrast guidelines and were reviewed for readability by design and accessibility specialists.
- *“Good design saves lives. When healthcare is designed without us, it becomes dangerous.” — **Phillipe Genus**, Graphic Designer*



The Digital Toolkit: Empowering Staff and Patients

Toolkit Overview



The BHSS Sickle Cell Digital Toolkit was developed to extend the campaign beyond awareness, providing practical tools for education and advocacy. It was informed by patient testimony, clinician feedback, and BHSS's ongoing Advocacy Training Programme.

The toolkit includes two integrated learning streams — one for healthcare professionals and one for patients and carers.

For Healthcare Professionals



- Inclusive Design Audit Framework
- Pain Management Guidelines for Sickle Cell Patients
- Bias Recognition Exercises
- Case Studies of poor and exemplary practice
- Templates for reflective learning and departmental action plans

For Patients and Carers



- Advocacy scripts for use during clinical consultations
- Information on legal rights under the Equality Act (2010), Human Rights Act (1998), and NHS Constitution (2015)
- Self-management resources and care-plan templates
- Signposting to community support organisations

For Designers and Innovators



- Inclusive Design Principles (language, interface, and imagery)
- Checklist for digital health tools ensuring accessibility for darker skin tones (addressing pulse oximeter bias)
- Guidelines for participatory design with underrepresented groups

The toolkit was accessed via QR code and continues to be used in BHSS's professional training sessions and academic partnerships.

"I have educated myself about the inequalities that sickle cell patients face. I think more healthcare professionals need to understand what it feels like to walk in the shoes of someone living with sickle cell."

— Healthcare Professional

Qualitative Impact



Feedback from patients, carers, and healthcare professionals revealed profound emotional engagement and reflection:

"These images show what we go through, the fear, the exhaustion. If people see that, maybe they'll stop questioning our pain."

— Sickle Cell Patient

"This campaign gave language to what we've been feeling for years."

— Parent of a Child with Sickle Cell

"We send patients to specialists for sickle cell but, this campaign made me realise how much I don't know. It should be part of our training."

— NHS Professional

These responses underscore the campaign's success in making invisible pain visible, bridging understanding between patients and professionals.

Strategic Learning



- 1. Visibility Is Impact:** In health inequalities work, visibility itself is intervention, it changes perception, prompts conversation, and challenges bias.
- 2. Measurement Must Be Contextual:** Quantitative engagement cannot fully capture emotional or systemic impact in creative health advocacy.
- 3. Co-Design Ensures Authenticity:** Patient-led creation leads to accurate, resonant messaging and sustained trust.
- 4. Integration Matters:** Linking the campaign to BHSS's advocacy training programme extended its lifespan and deepened learning outcomes.

Strategic Priorities for 2025–2026



Building on the success and learning from My Pain Is Real: Designing for Equity, BHSS will continue to advance systemic reform through creative advocacy, data-led evaluation, and collaborative design. This next phase focuses on **expanding reach, influencing practice, and embedding inclusive design within the health sector.**

1. Embedding Inclusive Design in Healthcare Education

BHSS will partner with NHS trusts, training providers, and universities to integrate inclusive design and anti-bias modules into professional development. This will build on the Sickle Cell Toolkit, ensuring that design literacy and cultural competence become core competencies within health and care education.



2. Expanding the Sickle Cell Toolkit

The toolkit will evolve into a **digital learning platform** with interactive case studies, videos, and assessment modules. This online expansion will allow NHS teams, students, and designers to complete accredited learning at scale.

3. Establishing a Patient-Led Advisory Panel To maintain authenticity and accountability, BHSS will convene a **Sickle Cell Patient Advisory Panel** to guide ongoing campaign development and evaluate NHS partnerships. This ensures lived experience continues to drive design and delivery.

4. Integrating the Campaign into the BHSS Advocacy Training Programme

BHSS's advocates will use the campaign and toolkit as a training module within their community and professional outreach. This integration will strengthen the link between visual advocacy and day-to-day patient empowerment.

5. Influencing Policy and Commissioning

BHSS will work with Public Health Birmingham, NHS England, and policymakers to translate creative campaigns into structural reform from data collection to commissioning frameworks. This includes advocating for **equity-based commissioning models** that fund community-led innovation.

Key Recommendations



- 1. Design with Inclusion from the Start:** Policy and healthcare design teams should co-create services with affected communities, not consult them retrospectively.
- 2. Invest in Community-Led Advocacy Infrastructure:** Funders and commissioners must resource grassroots organisations that provide culturally competent interventions.
- 3. Embed Equity Metrics in Evaluation:** Success should be measured not only by outputs but by trust, accessibility, and representation.
- 4. Recognise Creative Advocacy as Systemic Reform:** Campaigns like My Pain Is Real should be treated as catalysts for policy change, not as peripheral communications activity.
- 5. Ensure Patient Voice in Decision-Making:** Establish permanent patient panels across NHS pathways to sustain inclusive feedback loops.



Conclusion and Acknowledgements

Conclusion



My Pain Is Real: Designing for Equity campaign stands as both an artwork and an act of reform.

It challenged institutions to see, listen, and redesign. It reminded healthcare professionals that **belief is a clinical intervention** and that inclusive design is not aesthetic, but ethical.

Through visual storytelling, digital learning, and lived experience, BHSS has begun to bridge one of the deepest gaps in modern healthcare: the gap between intention and inclusion.

The campaign has laid a foundation for long-term systemic change. Its impact will continue to inform how professionals train, how patients advocate, and how design decisions are made.

Equity begins with design. Design begins with empathy. Empathy begins with listening.

Acknowledgements



Partner:

- Paul Hamlyn Foundation

Collaborators and Contributors:

- Phillipe Genus – Graphic Designer
- Rachel McFee – OSCAR Birmingham
- Sickie Cell Patient Co-Design Group
- BHSS Advocacy Trainers and Volunteers

Advisory Committee (2025):

- Stacey Bryan – Chair, British Caribbean Doctors and Dentists Association
- Phillipe Genus – Graphic Designer
- Aundre Tulloch – Doctor
- Dr Ishtar Govia – Psychologist and WHO Health Consultant
- Sian Duckworth – User Experience Designer
- Anikah Cobblah – SEN Teacher & BHSS Co-Director
- James Simmonds – Immigration Advisor
- Dareece James – Data Scientist
- David Mowatt – Youth Behavioural Expert

Leadership:

- Natalie Scarlett – Executive Director
- Anikah Cobblah – Co-Director
- Matthew Henry – Co-Director



Special Thanks

To the sickle cell patients and families who shared their experiences, the creative and advocacy teams who built this campaign, and the communities who continue to fight for visibility, dignity, and design equity.

