

Visual griot: Bringing history of SCD to the present.



You & I

In a significant milestone, the Sickle Cell Society marked its 40th anniversary in 2019. This was also the year when the Society received a substantial grant from the HLF, leading to the launch of **Our Journey, Our Story**. This pioneering project, funded by the HLF, delved into the history and memory of sickle cell disease (SCD) in the UK since the arrival of the Windrush generation, using oral histories and archives.

It was necessary and crucial as although, for over a century, SCD, one of the fastest-growing genetic conditions in the UK, has been medically recognised as a health condition, awareness of it remains low, and people with SCD are still facing stigma¹. That is why, within this project, the SCS brought an exhibition at the Black Cultural Archives, which aimed to raise greater awareness about SCD and highlight the links between SCD and the history of Black radicalism in Britain. The exhibition captured this history through the eyes of people and families living with sickle cell as they told their stories of illness, action, identity, and inheritance. It brought oral histories with photographs, art, and archives about the history of sickle cell activism to tell an important story about the fight against health inequality in Britain.

The Sickle Cell Society commissioned Larry Amponsah to create a piece around the charity's archives, and therefore, one should consider Larry's work through the lenses of this history. Larry's work is akin to that of a "griot." In West African societies, particularly Mande societies, the griot is the storyteller who preserves history and cultural knowledge from generation to generation. Through this piece, *You & I*, Larry Amponsah brings history to the present and gives life to the archives.

I-Role of the voluntary sector and the history of the Sickle Cell Society

¹ About 15000 people are living with SCD in the UK

Initiated by the Sickle Cell Society, "**Our Journey, Our Story**" aimed to raise awareness about the role of the voluntary sectors in advocating for SCD patients in a country where, seemingly, everyone had access to healthcare.

While the creation of the NHS meant greater access to healthcare, the Windrush marks the beginning of a period in which the British state was forced to confront the reality that both the "white British nation" and its tolerant self-image were myths, and to face the racism that had facilitated its overseas Empire " (Redhead, 2021). Therefore, while the NHS diagnosed people with SCD, this same system failed to address it adequately. Another paradox was even though the NHS relied heavily on Windrush immigrants, those same immigrants contributing to British society faced racism. Because of the state's lack of interest, the voluntary sector needed to advocate for sickle cell patients within the NHS.

Two key figures, Elizabeth Anionwu² and Neville Clare, founded, respectively, the **Sickle Cell Society** and **OSCAR**³. They were deeply influenced by Black radicalism, having both visited the SCD support groups in the US. Indeed, in the seventies, groups such as the Black Panther, through their advocacy, pointed out the discrimination in the American health sector and developed a sickle cell screening programme. Elizabeth Anionwu, a nurse, witnessed the need for more knowledge from the medical sector. She was the first specialised sickle cell nurse practitioner. The role of SCD nurses was crucial as they were a bridge between the SCS community and the health care providers.

Moreover, the Sickle Cell Society, as well as OSCAR, produced leaflets and patient information documentation, which provided counselling, raised awareness in school, and ensured the patient's voices were heard.⁴ SCS and OSCAR operate on several levels. The initial leaflets produced by the SCS advocates for better conditions for SCD patients. Later, the focus was on screening and raising awareness amongst the communities. The archives, composed of newsletters, photographs, and campaign leaflets, highlight a history of campaigning and how they constituted a tight-knit community (Redhead:2021). Children's holidays, poetry prizes, and birth celebrations demonstrated the importance of caring for each other within the community. It also emphasises the solidarity and positivity in the SCD community.

The archives are telling stories. One often thinks archives belong to the realm of the past and are static. Nevertheless, archives talk about the past, the present, and what we value. Therefore, by going through these archives, Larry's piece emerged and encapsulated notions of care, pain, and resilience within the sickle cell community.

II - You and I, in Larry's words

As an artist, I try hard to solve some of the unresolved questions of representations in art history by reviving the black image to its most authentic form to renegotiate the terms and canon through which blackness is seen. I do this by employing collage as my point of entry to create fictional but familiar images and meaningful narratives while staying close to the actual language of painting and some unconventionally developed new forms.

You & I (I&II) were made with historical images from the Sickle Cell Society's archives and newsletters as well as images collected from friends who have sickle cell; they were made to

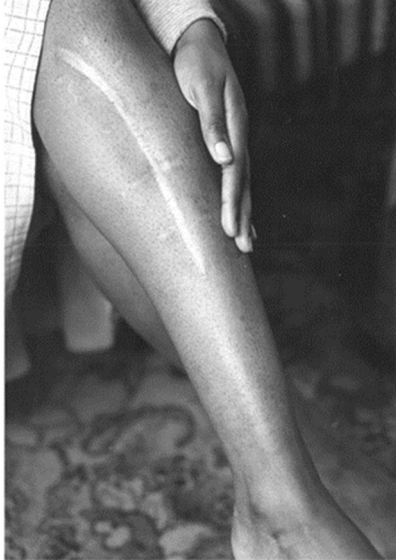
² In 1979, she helped to establish in Brent the first nurse-led UK Sickle & Thalassaemia Screening and Counselling Centre

³ Neville Clare (1946-2015) was diagnosed with sickle cell-haemoglobin C (a variant of sickle cell disease) in 1967. In 1975, frustrated by the lack of knowledge around the condition, he established the Organisation for Sickle Cell Anaemia Research (OSCAR).

⁴ Multiple voluntary organisations emerged in the 1970s and 1980s, to champion the cause of sickle cell patients.

encourage the significance of creating comfortable atmospheres of support for SCD patients during the episodes of pain, which they go through in many occasions on many levels.

In the diptych is a couple supporting each other through an episode of pain. The woman is looking between the guy and the person looking at her. She is communicating between two people at the same time. I didn't want the idea of pain to be off-putting; on the contrary, the audience should be able to look at it. I was particularly inspired by one image of a scar. By



seeing someone subjected to pain having extra pain, it was essential to turn it into something hopeful. The idea was to replicate the scar in the work by tearing the images both intentionally and unintentionally. I was destroying images to build new ones. Sickle cell is an invisible condition, and the pain associated with SCD is equally hidden. Therefore, art has often been a means to express and visualise the challenges for people living with sickle cell.

With art come responsibilities, so I understand what it means to move art away from a mere commodity into something that serves as a platform for knowledge sharing and the importance of seeing art as a gift to our audience and the communities we belong to. The topic was exciting and challenging since I had never used art to tackle health issues. But this health issue stood out; it was dear to my heart as I know people with sickle cell, and I also lost a family friend to it in the past. I remember in 2015, on my graduation day after my first degree, my late friend's mom came, and she was so happy. While celebrating with my family and me, she whispered to me, "Junior would be graduating today with you as well if he was here; I miss him so much," that broke my heart and stayed with me for so long. So, when this project came to me, it felt like something I had always been waiting for, something that was meant to be. It became my opportunity to use this project to honour all those living with sickle cell and also to support all those who have lost family and friends to sickle cell.

*A scar from an unnecessary sickle cell operation on a person with sickle cell disease.
@ Sickle Cell Society
Archives*

In November 2021, the Sickle Cell Society published an inquiry into Sickle Cell Care titled 'No One's Listening Report.' Moreover, throughout "Our Journey, Our Story," the society collected 30 oral histories from patients and health professionals. They all mentioned not only the invisibility of SCD but the invisibility of SCD patients within the health care system. Images are powerful. As a black artist, Larry Amponsah felt the responsibility to create images that can be juxtaposed with sickle cell and the pain it comes with, and this is because he understands the power of images and genuinely believed that if more artists, institutions like the Sickle Cell Society and Wellcome Collection continue to invest in projects like this, then we can truly make a change.

Bibliography

Neville Clare, *An OSCAR for My Troubles: A Life Working for Better Understanding and Treatment of Sickle Cell Disorder* (Writersworld Ltd, 2009).

Elizabeth Anionwu, *Mixed Blessings from a Cambridge Union* (London: ELIZAN, 2016).

Simon Dyson, *Sickle Cell and the Social Sciences: Health, Racism and Disablement* (Routledge, 2019).

Grace Readhead, 'The history of sickle cell anaemia in postwar Britain', PHD thesis, 2021).