Haringey Advice Partnership
Supporting Your Community

healthwatch Haringey

# Supporting People Living with Sickle Cell Disease in Haringey

## September 2024 (summary)

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# Executive summary

This report is the product of a project about the experiences of people living with sickle cell in Haringey and the challenges they face around accessing benefits and services. The research was commissioned by and delivered with Haringey Advice Partnership, a service led by Citizens Advice Haringey that provides information, advice and guidance to Haringey residents.

Sickle cell patients face a range of psychosocial challenges which also impact their families and close friends. Addressing these challenges can help to better support people with sickle cell in the management of the condition. Many people with sickle cell report that there is often a low priority and scant attention given to the challenges around workplace discrimination and accessing benefits on the part of practitioners and healthcare professionals. This is on top of already facing stigma, delays in care, allegations of exaggerating their condition, being discredited, racism, microaggressions, inadequate pain management and poor assessments.

Social support initiatives can lead to enhanced quality of life and better coping with the condition. Primary and secondary care in North Central London has faced hefty criticisms for being slow to address the concerns of people with sickle cell disease, but it is apparent that there are positive moves to address longstanding issues at North Middlesex Hospital and the George Marsh Centre. This is testimony to the realisation that there is a necessity to address the concerns of people with sickle cell in Haringey and North London more broadly. The 2024 launch of the new Community Red Cell Service for Adults with Sickle Cell, Thalassaemia and Rare Inherited Anaemias is also a demonstration of increased recognition of red cell disorders locally.

# Recommendations

- Enhancing the function of sickle cell centres which have staff trained in managing the conditions are key and have been shown to result in reduced anxiety among patients with sickle cell disease.
- Developing better integrated support for accessing benefits for people with sickle cell and supporting people with sickle cell around employment.
- Increased understanding of psychosocial issues with a greater focus on the wellbeing of people with sickle cell, such as wellness interventions and emotional support.
- Providing training for healthcare professionals regarding sickle cell disease which address management of the condition, patient needs, discrimination in primary and secondary care and raise awareness of implicit biases.
- Initiatives for trust-building among patients and medical professionals to reduce stigma.
- Focus on initiatives around nutrition and wellbeing which reduce sickle cell crises, disease severity and hospitalisations, thereby contributing to an improved quality of life.
- Addressing any pre-existing multifactorial environmental stressors such as poverty and food insecurity that contributed to the initial hospitalisation.

# Background and context

Sickle cell disease is the fastest growing genetic disease in the UK and is the name for a group of inherited health conditions that affect red blood cells. Sickle cell disease causes red blood cells to form into shapes like a sickle which do not live as long as healthy cells and block blood vessels, thereby causing fatal complications. These cells become hard and sticky and clump together and can restrict oxygen flowing anywhere that blood is supposed to go around the body. When this happens it is accompanied by difficulty breathing, tiredness and excruciating pain known as a 'sickle cell crisis' or 'vaso-occlusive crises' which eventually become chronic. The crises are both painful and debilitating, with there also being the potential for organ damage (Falvo, 2005: 243). There are 15,000 people in England living with sickle cell disease.

The sickle cell trait is common in people of African heritage, the condition developing because of regular mosquito bites in ancestors from Africa. Carriers of the sickle cell trait must also be conscious that if they go onto have children with a person who also has the trait – this increases the chances of the child also developing sickle cell anaemia. Those who go on to develop sickle cell anaemia need regular blood transfusions and associated conditions must be managed such as strokes, lung conditions and anaemia. Yet with this, blood has to be matched in order to reduce the risk of serious complications. Blood type matches can only be made in half of requests according to the NHS and patients often have to rely on using O-negative as a universal blood type.

A million blood donors are needed over the next five years to ensure patients get the right type of blood.

For people with sickle cell there are issues around income maximisation and access to benefits and employment, as there are challenges related to employers and people with sickle cell disease taking time off. In terms of access to benefits, people with sickle cell and thalassemia struggle to get PIP (Personal Independence Payment) due to the fluctuations of their condition, more than other health groups. In the North Central London area, consultants from the Whittington Hospital have written support letters for sickle cell disease patients. This demonstrates the importance of people with sickle cell being aware of their rights and legal protections.

# Experiences of people with sickle cell in London and the United Kingdom

It has long been noted that sickle cell is both under-researched and under-resourced and not given a priority in the health service (Cashmore, 2004:439). Macdonald in his book ***Primary Health Care: Medicine in Its Place*** (1992: 131) highlights that until black communities began to bring attention to sickle cell, health systems afforded little attention to the condition. Dyson et al in 2016 highlighted how stereotypical and racist perceptions of black people have been part of the barrier to sickle cell patients accessing services.

Dr Lola Oni (2023) notes that it was in 1974 that the Organisation for Sickle Cell Anaemia Research (OSCAR) began its activities more officially, while Chouhan and Nazroo (2020: 88) noted that OSCAR was key in pushing the NHS to ensure that due attention was given to sickle cell and that newborns were screened for sickle cell, with screening only starting in 2003.

Oni (2023) highlights that the development of community specialist centres in the UK was a landmark victory for supporting those with sickle cell disease. The first specialist sickle cell centre in the UK was in Brent in 1979 and was established by the late Dr Milica (Misha) Brozović and Elizabeth Anionwu (now Dame) at Central Middlesex Hospital. Nurse Elizabeth Anionwu describes in her book ***Mixed Blessings from a Cambridge Union*** visiting a hospital in 1976 where she saw a girl crying under the bed clothes in pain who had been there for hours. Anionwu states that she called a nurse and stated that she would not leave until an analgesic had been administered. The protections of black nurses however had to struggle against racist ward sisters some of whom felt that black people with sickle cell were merely high on drugs.

The new centres enabled community awareness, promoted family support, educated other healthcare professionals and encouraged access to screening and counselling.

The key people and organisations during the 1970s and 1980s were:

- Neville Clare, OSCAR and the Haringey, Enfield and Barnet Sickle Cell Group.
- Dr George Marsh, who based on the activities of the above, campaigned for a sickle cell centre to support those with the condition. This led to the formation of the George Marsh Centre in Tottenham.
- Dame Elizabeth Anionwu, Dr Brozović and the Brent Community Health Council which led to the formation of Brent Sickle Cell and Thalassaemia Centre (BSCTC).
- The Camberwell Community Health Council.
- The Sickle Cell Society, and its branches in Islington and Harlesden.

Elizabeth Anionwu in 1988 in her PhD dissertation recounts an experience in 1980 with Camden and Islington Health Authority wherein it was inferred that black communities were not educated enough to understand genetics and the high number of single black mothers would make it difficult to trace fathers for screening. It was insinuated that they were promiscuous and were in unstable relationships as they were not married. This was even though partner screening was in place for thalassemia in the borough and was associated with Cypriot and South Asian communities. Anionwu noted that these cultural judgements were made by white male middle-class members of Camden and Islington Health Authority at the time.

# Primary, secondary and tertiary health care and sickle cell

Some healthcare workers within some hospitals do not even know what sickle cell disease is, which delays essential care when needed during a crisis – if there are delays during a crisis the outcome could be critical. Moreover, during a sickle cell crisis, patients often require powerful opioid painkillers. These may not be administered due to a misplaced concern that the patient is exaggerating their pain levels.

In 2021 an All-Party Parliamentary Group on Sickle Cell and Thalassaemia found that there were "serious failings" for patients with sickle cell disease in England and several deaths which could have been avoided. The MPs' report also found evidence of racism as patients reported that on some occasions they had been racially abused by staff or had had their pain denigrated or regarded as exaggerated.

Although specialists in haematology departments were aware of the condition, in generalist parts of hospitals there is a complete lack of awareness. Patients find that they often have to battle for pain relief, battle a lack of trust in themselves, and battle an overall lack of understanding of the condition.

As a result of these experiences, some people with sickle cell disease try to suffice without even going to the hospital when they have a crisis, as they anticipate the response which they will face at hospital as being negative. Hence, people who live with sickle cell disease often do not even bother to seek out medical care. Their pain, which is often excruciating, must be believed and not regarded as being either an act or an exaggeration.

# Sickle cell in Haringey and North London

In the 1970s Neville Clare and Organisation for Sickle Cell Anaemia Research, aka 'OSCAR', based in Haringey, began bringing attention to the struggles and experiences of people with sickle cell. Neville Clare had sickle cell anaemia himself and along with nurse Suzanne Treasure, founded the Haringey, Enfield and Barnet Sickle Cell Group (Crown, 2010). Treasure was a nurse for many years and then after 1985 worked more with people with sickle cell and she would train doctors and nurses at North Middlesex Hospital[2]. Others such as Majorie Ferguson, also emphasised the importance of screening and educating families about sickle cell.

In 1989 the George Marsh Sickle Cell and Thalassaemia Centre at St Ann's Hospital in Tottenham was officially opened. It was named after Dr George Marsh, a consultant haematologist at North Middlesex Hospital, who became aware of the independent sickle cell support group in Wood Green (the Haringey, Enfield and Barnet Sickle Cell Group), which comprised many of his own patients. He then campaigned for a space to be established for people with sickle cell in North London. When the centre was opened information was provided at the centre, seminars and workshops held and social events would also take place. Staff were also based here and later screening would occur here.

'Above the Pain' was an organisation which began in 2013 as a name for the support group in Tottenham, while in Enfield, 'Sickle Cell Cause' developed. Both still utilise the George Marsh Centre but have separate activities.

Yet between 2016 and 2019, the George Marsh Centre was effectively closed and access to it was restricted for local people in North London who had sickle cell. The centre which was established for people with sickle cell seemed to now be utilised for other purposes and less so for people with sickle cell.

In April 2019, Evan Smith died after developing sepsis which triggered a sickle cell crisis following a procedure to remove a gallbladder stent a week prior. He was 21 years of age and rang 999 from his NHS hallway hospital bed at North Middlesex Hospital because he was so desperate to get treatment. Staff did not adequately comprehend sickle cell disease (Oni, 2023). North Middlesex Hospital came under scrutiny in 2022 in regard to its services for patients with sickle cell disease. The Care Quality Commission (CQC) in 2022 told North Middlesex Hospital Trust to make improvements for patients with sickle cell disease as an unannounced inspection revealed that the pace of embedding improvements was slow and that learning had not been prioritised by the Trust.

[2] Meeting with Noel Gordon in December 2023 at the George Marsh Centre.

The CQC relayed an incident wherein a sickle cell patient who was in severe pain was made to feel like a drug addict merely for requesting pain relief. The CQC also mentioned that North Middlesex University Hospital was not alone in such failings and in not adequately understanding the specialised treatment needed by patients with red blood cell disorders.

The CQC also found:

- A range of incidents occurred relating to medicines not being available or errors in administering medication – yet not all incidents were reported.
- The North Middlesex Hospital Trust did not adequately engage with the local community to understand the needs of people who live locally with sickle cell.
- CQC inspectors found that there were significant delays in administering pain relief to sickle cell patients. This was despite guidance from the National Institute for Health and Care Excellence (NICE) that all patients experiencing a sickle cell crisis should be treated as a medical emergency.
- The service focused too narrowly on the physical health of patients and there was limited support for their psychological and psychosocial needs.
- There was no access to dietitians, physiotherapists, occupational health professionals and holistic assessment and support for patients' complex needs.

Since the CQC report, there have been significant improvements which have been made by North Middlesex Hospital which Healthwatch Haringey has observed.
For instance, on the Haematology Day Unit the plan is for there to be eleven new positions:

- Two advanced nurse practitioners
- A community arm with a community matron
- A service manager
- Three Band 7 nurses
- One Band 6 nurse
- One Practice Development Nurse
- Additional consultant time
- Additional registrar time

As of 2024, Disability Action Haringey conduct Reiki, hypnotherapy and hand massage therapy sessions at the George Marsh Centre for people with sickle cell and thalassemia. These sessions take place on Thursday evenings, 5pm to 8pm, on Fridays from 11am to 7pm and a Saturday, 12noon to 5pm. Sessions are open to patients from Whittington Hospital or North Middlesex Hospital, and anyone who lives in any NCL borough.

Moreover, NCL ICB (Integrated Care Board) is taking further steps to address the challenges faced by people with sickle cell disease and make better usage of the George Marsh Centre. This includes the formation of a new service to support people with sickle cell around psycho-social issues. Information about the service has been co-produced with people with sickle cell and June 2024 will see a soft launch of the new service along with community engagement.

The new service will include:

- Sharing learnings across other sickle cell services around London and working with other Trusts.
- Enhancing community nursing for sickle cell.
- A benefits advisor.
- Psychological support.
- Community pharmacy for people with sickle cell.
- Recruitment and employment advice.
- Vocational therapy and rehab.
- Signposting support for people with sickle cell.
- Promoting work via NCL ICB's Red Cell website.
- Making the website more user-friendly.

# Employment and accessing benefits for people with sickle cell

> "Some people with it can't hold down jobs or continue in education. It can break families up. Some parents whose children have the disease can't go and work because they have to care for the child. In one family, there are two children who have the disease and they are sometimes in hospital."
>
> Suzanne Treasure, nurse (Crown, 2010)

People with sickle cell have historically struggled when it comes to accessing welfare benefits, as the condition is not necessarily visible as is the case with other disabilities and chronic illnesses. Moreover, as people with the condition may fluctuate it is often regarded as not being a condition which requires the same level of due attention.

In October 2022, MP for Lewisham Janet Daby posed a question to the HM Treasury as to whether the then Chancellor of the Exchequer had made an assessment of the adequacy of Government support for (a) fuel and (b) other costs for people with sickle cell disease during winter 2022[3].

People with sickle cell may experience high rates of unemployment due to poor job skills, challenges with cognitive function, low self-esteem or difficult interpersonal relationships with colleagues in the workplace or management (Williams et al., 2018) Dyson et al. (2021) have discussed that illness-absences are an only-partially-modifiable feature of sickle cell disease (SCD), as a result "disability rights advocacy that asserts disabled people do not exhibit lower productivity/increased sickness-absence presents a challenge for workers with SCD".

Individuals with sickle cell disease when embarking on employment have to think about the potential physical demands of a job and also the impact of strenuous exertion in triggering a sickle cell crisis (Falvo, 2005: 244). Hot weather may also place strain on the heart and causes dehydration which can trigger a crisis. Hence, working outside in very hot or very cold weather may pose problems to people with sickle cell and hence working indoors may be an option for people with SCD.

[3] https://www.parallelparliament.co.uk/question/59240/sickle-cell-diseases-government-assistance

# Methods

For this project the research methods utilised were as follows:

- Semi-structured interviews with key individuals in Haringey who have sickle cell disease.
- Semi-structured interviews with healthcare professionals working with people who have sickle cell disease.

These methods were particularly important for this project for the following reasons:

- Facilitating engaging people early and learning the landscape.
- Semi-structured interviews allow not only for a rapport to be formed between interviewee and interviewer, but also for probing and follow-up questions, thereby offering deep insights from interviewees.
- Hearing experiences of people with the condition and hence providing good quality insights from participants.

## Interviews

The lead researcher conducted a total of six interviews:

- Four interviews with people who have sickle cell disease in Haringey.
- One interview with a current consultant haematologist from the North Middlesex Hospital.
- One interview with a healthcare professional who will be rolling out a new support service.

# Findings

In this section, the findings from the interviews will be presented.

## Key themes from interviews

After the interviews with key participants these were the main themes which emerged:

1. Experiences with sickle cell crises
2. Traumatic experiences within healthcare settings
3. Managing chronic pain for people with sickle cell disease (SCD)
4. A lack of knowledge of the condition across primary, secondary and tertiary care
5. A lack of employment and benefit support
6. Haringey as a borough of sickle cell health activism
7. The medicalisation of people with sickle cell
8. The NHS and historic institutional racism
9. Improvements at North Middlesex Hospital and across North Central London

## Theme 1: Experiences with sickle cell crises

The participants who were interviewed described a range of experiences when it came to sickle cell crises.

> "My school years started in South London, and that was a challenge, going to school every day back in the day. At play times, like in primary school, you had a play time, a lunch time and then another play time. They would put you out there whether it was snowing, raining, sleet, whether the sun was shining, you had to go out there. I just remember these play times, just being huddled up at the door because if you'd try to get in they would kick you back outside, you had to be outside..."
> Interview with AA, dated 21 February 2024

> "I first had issues with sickle cell when I was four. My mum took me to Stoke Mandeville Hospital, then our friends ... hospital to have my teeth extracted at four, baby teeth. And I woke up and there were four doctors holding me down, giving me a blood transfusion. I found out later they discovered that I had sickle cell. But there were lots of issues around it because when I got better ... my dad hit the roof because you know 'He came in healthy, why is he sick?'."
> Interview with CC, dated 18 December 2023

"About six months ago I had a major crisis. I thought I was dying. I went to hospital, they did give me pain relief, but then I was just left on the trolley, because there's nothing else they can do…. It was okay, I was given pain relief and I was just left on the trolley like I said. The doctor just came and said, 'look you just had a sickle cell attack'. That was it, that's all he said."
Interview with DD, dated 21 May 2024

"As an adult… I was playing football, and I had a crisis so I went to hospital for it. I had to go to cause it's that intense the pain and doctor says, You've got to give up playing football'. So I said, 'Oh fair enough, I can play cricket or something.' And the painkillers they give us, was painkiller injections. Pethidine, it works very quick…its intermuscular…"
Interview with CC, dated 18 December 2023

## Theme 2: Traumatic experiences within healthcare settings

Nearly all participants mentioned traumatic experiences while being within healthcare settings with the condition. This was more pronounced among participants who had lived through the 1970s and 1980s.

"I remember being told, well I wasn't being spoke to, the crowd around the bed, my parents were sort of huddle up in the corner, my mum was crying and had her head on my dad's shoulder, and I remember hearing 'Yes, I would say 14 to 21 years at most'. That is something which has lived with me, and when I met other sickle cell warriors, you know, from my era, my generation, we all realised that we all had 'sell-by dates', where they had a life expectancy for you to live. So that gave them license to feel that they can test and do anything because we wasn't expected to live."
Interview with AA, dated 21 February 2024

"They sent me there [to a special school] cause I had this condition called sickle cell, but it was just a tick box exercise. I'm black, their perception is I'm retarded, so they stick me in the boarding school… I went swimming, I had a crisis after swimming, they put me to bed… I was about 11 when I had a crisis. So I thought, I'll go to the shallow end and I'll try and swim across, so I get, not even halfway and I get this pain in my waist and it's the sickle cell. I'm having a crisis because I'm doing physical exercise without any preparation, without any exercise beforehand like a warm-up. So, I have a crisis. So when we get back to school I'm saying I'm not feeling well, I've got pain so they put me to bed and they give me a hot water bottle and ring my mum. They come back, about 2 hours later, take me home and my mum gives me some of her painkillers."
Interview with CC, dated 18 December 2023

A participant who had more recent experiences within secondary care discussed the impact traumatic experiences have on exacerbating pain:

> "So how do you think that type of person is going to respond next time? They're going to be mute. They're going to feel like they can't show emotions. They're going to feel like they have to be strong. They're going to be crying inside. They're going to have to wipe their tears quickly. It changes someone and it's not kind. So, this is what I'm saying. So much of the damage can be done when you're actually, you know, interacting with other health carers because they put their stress onto you and before you know it, you feel a whole different type of way. Your stress level rises, your blood pressure goes up, you know, your pain increases, your ability to communicate next time is just not there"
> Interview with EE, dated 25 February 2024

## Theme 3: Managing chronic pain for people with sickle cell disease

Participants discussed how they managed sickle cell disease, and some mentioned a range of approaches they adopted which they found useful. Monitoring nutrition for instance was adopted by one participant. While others had to have more invasive procedures.

> "Like I was saying, I had a crisis in my left hip. But it wasn't bad enough to go to hospital for it. It was bad though and normally this dissipates with fluid and rest. But I wasn't resting as much as I should've rested. I started walking on it again when I got a place at university. It started to deteriorate, made it worse, like too much too soon on it... 'cause they told me 'keep it mobile' [so] I kept it mobile. The doctors are idiots... they treat us with all the same brush... my gut feeling was I should've just taken that year out. [I'd] not realised it, the hip, was gonna get worse. So I had to have it replaced."
> Interview with CC, dated 18 December 2023

Another participant discussed the significance of diet and nutrition in being useful for her in managing sickle cell:

> "...to try to refrain from eating certain foods, because our blood is sticky and gets clogged in the veins, so try to eat foods which give water and oxygen. Try to stick to single item foods rather than all of this processed stuff that you don't know what you're eating. You're eating glue, this thing is making your blood cells stick, and that's why you're in hospital every month having blood transfusions because your blood is sticking, and then you have to get it removed and then get somebody else's blood..."
> Interview with AA, dated 21 February 2024

Another participant however mentioned that she was concerned about being thought of as a substance misuser merely for asking for pain relief within hospitals,

> "I don't know how to explain it, like your whole-body aches. When you go to hospital they give you what they can, like you're screaming for pain relief but then you're a bit worried they might think you're a junkie. You know so you don't want to answer too much, they can't give you too much either because when I had the attack my blood pressure was so low there's only so much morphine your body can handle."
> Interview with DD, dated 21 May 2024

In terms of managing chronic pain without painkillers, a participant mentioned:

> "Yeah, Tai Chi helps. But in the mornings, I've still got this pain. I've still got this bad pain in my lower back... And I think ... when I first started these painkillers, they were really effective, but I realised that... because it's therapeutic as well, you actually feel better. Sometimes your body has its own painkillers. The ones they give us it's called – OxyNorm (oxycodone). They are opioids. It's dangerous, it's dangerous for the body and all that. So I have to wean myself off. But I've still got that chronic pain. That's still, it's an issue to deal with... I never had that pain before... that's why I could get so much done. But now... I try and do the Tai Chi and all that. It helps and the massage and all that."
> Interview with CC, dated 18 December 2023

## Theme 4: Lack of knowledge of the conditon across primary, secondary and tertiary care

Participants mentioned that they had still experienced a lack of knowledge about sickle cell across primary, secondary and tertiary care:

> "I had my left one replaced 2019. I had a shoulder ... replacement cause it ... the same problem with the hip, happened in my left shoulder. See when it comes to sickle cell right, they treat us all the same. You got sickle cell; this drug will do for you. You're all the same. But we're not. Our physiology's a little bit different in the way we respond to drugs. They don't see us like that. It's a white man's system dealing with black people and we're different... They don't take into consideration that we're all different."
> Interview with CC, dated 18 December 2023

A similar sentiment was also reiterated by another participant who said:

> "You have to remember that everyone's an individual and they, in sickle cell, how they're affected is very like on an individual circumstance…Yes, it is under the same umbrella, but it's slight nuances that make this person suffer a lot different."
> Interview with EE, dated 25 February 2024

## Theme 5: A lack of employment and benefit support

Navigating the welfare benefits system and employment was a constant struggle for people with sickle cell, and several participants highlighted this.

> "In the 80's when I [was] working, I've had so many jobs and I learned very early not to put 'sickle cell' on the application form, you know, when they ask you if you have any illnesses and so forth. I learned pretty early not to put that on or they wouldn't employ you. When I did fall into crisis, and go back into work three days later or a week later, 'Oh, she was alright the day before', they don't believe, there's no belief. So I went through many jobs. What I did do, I started being a Temp. I worked for an agency so that I wouldn't be letting my colleagues down and so forth. Doing agency work was good, because I chose my own hours [and] my own days, and I told them that I was unable to work and I got paid for when I was. So nobody could sack me because I was employed by the agency."
> Interview with AA, dated 21 February 2024

> "When it comes to the benefits, if you know someone's got chronic sickle cell and there's no cure for it, why keep putting us through these tests? They're worried about people misusing it, you know, misusing the benefits. But my condition… I can't misuse it, I've got a valid condition. I've had both my hips replaced; my shoulder replaced. Got chronic backache and all that, chronic fatigue. What's the issue? Why do you keep sending me through reviews?"
> Interview with CC, dated 18 December 2023

> "…If I said that I have cancer and I need to sign-on, I need to go on Disability Living Allowance they would say 'Ok, you've got cancer, let me just help you fill out the form. You're entitled to this, this and that.' Now if you go and say that you've got sickle cell, you have to prove it. You have to get doctors letters, you have to go to… medicals, you have to do all different type of things, 'Can you walk this far?'… and even with a doctor's letter it's not recognised.
> Interview with AA, dated 21 February 2024

The clinician we spoke to also mentioned the importance of providing holistic psycho-social support for people with sickle cell:

> "Employment advice, sometimes I think we take it for granted, [the] majority of sickle people are actually out there working. Those not working get frustrated because they're not able to find suitable employment. And then money advice and guidance, and then obviously the emotional support. Then they do get a lot of relationship issues. Since I have been here I've been hearing of different people that have been overusing the ED because they're going through divorce or the relationship has ended. So again, where do they go for these particular things?"
> Interview with BB, dated 16 January 2024

It was recognised however that this has improved considerably:

> "Let me put it this way: they do recognise it more now, but it's still a challenge. I do see that people are now getting benefits, it's not as tough. It is not as easy as the average Joe. You still need those letters. But now they recognising the doctor's letters."
> Interview with AA, dated 21 February 2024

## Theme 6: How the Windrush Generation navigated sickle cell

Some interviewees made reference to how some of the Windrush Generation approached diagnoses of sickle cell among their children.

> "Especially because they're from Jamaica, Jamaica's been under British rule since the 16th Century and they were invited to come and work here with their British passports. So they took the Englishman at his word, he actually took them at their word and they were like Gods so that was how, that transpired."
> Interview with CC, dated 18 December 2023

> "My parents didn't even know that they were carriers, they never heard of sickle cell. It was new to the UK you know. How it came about…my parents came from the Caribbean, Barbados to be precise, and we used to have aunts and uncles coming to visit regularly."
> Interview with AA, dated 21 February 2024

"But there were a few that were educated like Professor Gus John, Bernard Coard and they took the system on. When Bernard Coard wrote his seminal book – How the West Indian Child Is Made Educationally Subnormal by the British School System, they had to reform the system, they had to reform."
Interview with CC, dated 18 December 2023

"I think my parents, they saw themselves like as a guest in somebody's house. They're not gonna complain. I remember Benjamin Zephaniah who passed recently. He said his mum said she can't critique them, she can't critique this country because she sees herself as a guest in their house type of thing."
Interview with CC, dated 18 December 2023

Yet the same participant also credited particular local politicians for supporting people with sickle cell in Haringey:

"Bernie Grant at the time... he was really good at everything. Bernie Grant, David Lammy can't touch him. Bernie Grant was our man; he'd fight for us cause he came up through the unions, so he was used to that... dealing with these people... But that, that calibre of people are not around anymore. David Lammy came here once and that was it. Once."
Interview with CC, dated 18 December 2023

## Theme 7: Haringey as a borough of sickle cell health activism

Some participants outlined that Haringey became a hub for sickle cell medical activism due to the activities of Neville Clare and his organisation OSCAR.

"After moving up to North London, my mum met Neville Clare. He is the guy that started up the first sickle cell support group [and] research organisation, and it is because of him that the Sickle Cell Society and any other sickle cell organisation had the blueprint for any support group in the UK and Europe.
Interview with AA, dated 21 February 2024

"In the early 70's there was no understanding, in the 80's it was a bit better. By this time now OSCAR was in place and doing the rounds. But, even down the street if you were to ask, 'have you ever heard of sickle cell?' the majority would say no they haven't. Whether they be black or white. If you walk down St Ann's Road and ask people 'do you know there's a sickle cell centre in St Ann's Hospital' the majority of people would say that they don't know. So, spreading the word can be...a challenge."
Interview with AA, dated 21 February 2024

In terms of how sickle cell patients in Haringey and the wider North London area attained the George Marsh Centre, the history was relayed by a participant as follows:

> "Neville Clare started supported groups under the name 'OSCAR', and he used to hold it in Wood Green High Road where he used to work in some offices. So, after work we would meet up in these offices to have sickle cell support groups because there was nothing there, nothing in place. Now one time, the person that had the keys to let us in for the meeting hadn't arrived yet and it was raining hard and we were huddled on the High Road underneath umbrellas waiting for the person with the key to come and let us in. And who should drive down Wood Green High Street, but Dr George Marsh himself?"

The participant continues:

> "He was shocked to see a bunch of his patients out in the rain on the High Road. So, he stopped his car, because being in the cold and the rain this is going to cause a sickle cell crisis. He stopped the car, came out and asked us what we were doing. So, we said that we were going to have a support group meeting... at the time there was about fifteen of us outside... when the meeting started there was a good thirty, forty people. But at that time there was about fifteen of us. So, we told him that we was having this meeting and invited him to attend and he attended and was blown away and kept coming back. Then he vowed that we needed a space for ourself... and he campaigned, got his colleagues involved, MPs, the government, NHS, even him himself and us, we fundraised, and we did a lot of stuff. And then the centre was built.."
> Interview with AA, dated 21 February 2024

> "...Thalassemia affects many Greek people, so they branched out, done their own thing, because at the end of the day, they're white people, they got funding. They get more funding than we get. So they manage to do their own thing. They didn't want to be associated with us. Still got their own building in Southgate somewhere. That's how this building got started and Neville Clare, he used to be one of our advocates. He used to be a mentor, that kind of stuff. He helped us out a lot. But the doctors didn't really like him too much if he got involved..."
> Interview with CC, dated 18 December 2023

## Theme 8: Medicalisation of people with sickle cell

Interviewees reported that they felt overly medicalised and pathologised while having the condition, this was particularly the case for participants who lived through the 1970s and 1980s.

> "Going into hospital now, that is when they discovered, when I wouldn't heal… that I had this condition, sickle cell. So, from that moment on, I was something of a wonder, and I was always in teaching hospitals. At that time, I was living in Tooting so I was at St George's Hospital, which is a teaching hospital. So, every time the doctor came round for any reason, he was always surrounded by students. And everybody is having a prod, a touch, a feel, you know, asking [me] different questions. And that has been my life."
> Interview with AA, dated 21 February 2024

> "I moved to North London in 1979 under Dr George Marsh, another teaching hospital so it was very similar. I went through my pregnancies there, so I was a good guinea pig for them. A lot of testing, a lot of drug testing, a lot of finger poking, I know it was necessary for the advancement of knowledge for the medical profession, but throughout the 70's, when you're treated as just like a piece of meat and they're testing different drugs on you and then you have to suffer the consequences of these drugs and then they give you another drug and then another drug, it was like there was no compassion for human life."
> Interview with AA, dated 21 February 2024

One participant outlined what they felt needed to be the approach of staff:

> "…so sometimes, yeah, it can be a negative experience. You've got a contrast, but if we're talking about, to be honest, what can be improved, it's more of an understanding and more, like, more general compassion from the nurses because too many times I feel like they've learned the course, you know, they're coming in to now deliver care, but the care is not as it should be, and, you know, they're not having compassion."
> Interview with EE, dated 25 February 2024

The participant continued,

> "Not only that, you're going to deliver care to a vulnerable patient who's already facing their own stress, like you might be facing yours, and I can appreciate that. But this person's in the bed, probably barely can get up and walk and care for themselves, and they need you to administer medication through a needle. Like, your hand needs to be very, very friendly right now, but sometimes it's not. And then you might get a reaction from the patient where they're like, 'oh, like it's really, really hurt them,' the way they've delivered it. And rather than try to be compassionate and understanding, 'Oh my gosh, I'm sorry, I'm sorry… did I hurt you?' Too many times that nurse is just going to be defensive and act like, 'What, what, what, what's the issue? Why are you crying now?'."
> Interview with EE, dated 25 February 2024

The participant elaborated:

> "So, it needs to always be with tact, and you know with care and with a bit more patience. So, when you've seen people just stab it in with no care, when you've seen people just rush and squirting it over a two second period as opposed to a ten second period, these things matter. And then what do you think is going to happen after you put so much force, almost like you've stabbed them? You see what I mean? And that 100% is abuse. At this point in time, it's abuse that's basically being given in the form of care, if that makes sense. It's being disguised in the form of care. Okay, you didn't like the fact that this person had to ask for their medication as many times as they did. So now, every time you administer it to them, you made sure it came with a bit more force and a bit more pain. So that perhaps they'll think twice about asking again. That is cruel."
> Interview with EE, dated 25 February 2024

## Theme 9: The NHS and historic instutional racism

The NHS came under scrutiny by participants and they made reference to institutional racism being entrenched in the health system in the 1970s and 1980s.

> "When I was working in the NHS, and this guy said 'Down with the n****s', I thought, I'd better keep my mouth shut. Not say nothing. I just got the job… And when I did complain, they said 'Oh we know about him.' So, they knew he was racist… And to prove a point, they sacked me when I gave him training. They trained him… And then 18 years after, after I've been to university and all that, I've learnt about a tribunal. So, I got them to a tribunal – 2012. 21st Century now and they come with a barrister and the judge didn't believe a word of what I said. Not one thing, none of it. This is what we gotta put up with."
> Interview with CC, dated 18 December 2023

"The thing is, there was a lot of racism in them days. The NHS is institutionally racist. It's better now but it was bad back in the 1990s... And even now when I went to a tribunal, I should've had legal representation, but I couldn't get it. The system works against us, it don't [doesn't] work for us."
Interview with CC, dated 18 December 2023

A participant with more recent experience in hospital relayed that there was still stigma attached to young people with sickle cell:

"Because too many times what happens here is that we get labelled aggressive, young... you know, hood rats. As if we all are. And that can't be far from the truth. You're not seeing that here. You might see that from one or two individuals that might even have behavioural issues. But I don't even think things like that are being looked at. Do you know what I mean?"
Interview with EE, dated 25 February 2024

The participant felt that this led to healthcare professionals having implicit biases and preconceived ideas about young sickle cell sufferers:

"And then because we're named, we're stigmatised as being aggressive and rude and all of that, now it makes the nurses feel comfortable in maltreating us which that's not right either... not everyone but a certain group of nurses, they will come in and they'll just be scoffing and, 'Oh, I've got that patient', and they'll just be scoffing in disgust, like they have to look after this patient, almost acting like we're not a human. It's honestly really disheartening, because it's not nice to know that wow, the person looking after me absolutely can't stand my guts, and I'm not even trying to make her, you know, hate me, but yet you see it before even, you know, the treatments begun. So that becomes almost like a culture."
Interview with EE, dated 25 February 2024

The consultant haematologist also noted the following in regard to misconceptions which some clinical staff may have in regards to people with sickle cell:

"I don't think its misconception, I think it's a lack of education. I think in terms of health, it's around... the health economics as well because sickle cell doesn't tend to affect the white, blue-eyed people, it is more of the Black and Asian ethnicities, so I think that plays a role as well."
Interview with BB, dated 16 January 2024

She continued:

> "...because if the people who were responsible for commissioning for sickle, if they really thought it was top priority and top agenda then more money would have been put into education of people that look after sickle, not just in health but also in social services. I remember in East London we used to work jointly with social services, when PIP actually came in, local groups, the social services and employment welfare officers they all got in touch with us at the sickle cell centre and were asking us to come and talk to their staff about sickle cell and how someone could access their benefits and things like that, so we were more in touch."
> Interview with BB, dated 16 January 2024

## Theme 10: Improvments at North Middlesex Hospital and North Central London

The consultant haematologist further informed:

> "Since I have been here some of the workstreams that we've done we've managed to get patient-controlled analgesia as an option so they don't have to wait for nurses to give them the analgesia they can do that themselves. I've trained all the nurses that need to administer that..."
> Interview with BB, dated 16 January 2024

She highlighted:

> "And we're moving from screen more towards digital records as well. When I first came most of the staff were using paper records... including the individual care plans as well, they're all going to be digitalised. And with these care plans the people through the pathway including the ambulance crew can view, the patient themselves can view it as well, and the staff that provide the care for the patient can view it... that was something that was different. In East London a lot of our records are digitalised, but North Mid was still behind."
> Interview with BB, dated 16 January 2024

Regarding the prior capacity for patients with sickle cell in Haringey and the wider NCL area, she stated:

> "I think one of the reasons why things were lagging a little bit in North London is because there wasn't adequate people to do the job that is required to ensure people receive the care that is outstanding. You can't expect six people to deliver the care that is required for almost 600 people in North London."
> Interview with BB, dated 16 January 2024

She went on to explain one of the main challenges facing people in Haringey who have sickle cell:

> "One of the things I keep hearing, even from last year, is heating. So, in East London we used to give out heat vouchers during the winter months to everybody that's affected [by] sickle, and if they actually wanted something additional, I think there was a designated team within the councils that could actually support them with their heating bills. Now here, we don't have a catalogue where social services are and what it is that is available for people, not specifically for sickle cell but just signposting and things like that."
> Interview with BB, dated 16 January 2024

# Discussion of findings

In Haringey the role of Neville Clare, Dr George Marsh and others in bringing the needs of people with sickle cell disease to the fore was pivotal. It was on the back of the work and activism of Neville Clare and OSCAR in the area that North London became a key place for sickle cell health activism. This led to the establishment of the George Marsh Centre which delivered a range of support services for people with sickle cell. This is also discussed by Grace Redhead in her paper ***A British Problem Affecting British People: Sickle Cell Anaemia, Medical Activism and Race in the National Health Service***, 1975-1993.

The George Marsh Centre provided a lot of functions around welfare support, employment advice etc. A participant noted:

> "We had all of that in place before, we had a social worker in place, we had the benefits, we had careers people in place, you know. All of that was underneath the support group. Now that we have won back the centre as sickle cell patients, it was the patients that campaigned, it was us, we led it, we did the campaigning, the petitioning, going to parliament and all that, and won back our centre which was built for our purpose."
> Interview with AA, dated 21 February 2024

Another participant stated,

> "It was helpful in the sense that... because I could meet someone, talk to someone about my condition cause they've got the same condition... they're local and... the staff here would understand sickle cell and how to help us... Somebody working here, voluntary, wrote a letter for me and that's how I got my flat because that letter said – this person has sickle cell."
> Interview with CC, dated 18 December 2023

Nevertheless, between 2016 and 2019, the George Marsh Centre was effectively closed and access to it was restricted for local people in North London who had sickle cell. The centre which was established for people with sickle cell seemed to now be utilised for other purposes and less so for people with sickle cell. This action also links with wider national trends of decreasing specialist centres for sickle cell. Oni (2023) for example highlights that in London in 1998 there were 16 specialist centres, in 2010 there were 19, while in 2021 there were 15. So the number of specialist services has actually gone down since 1998, though peaking in 2010. In terms of community nurse specialists, in 1998 there were 58, in 2010 there were 81 and now there are 49. Again, a lower number than since 1998.

A participant noted:

> "Over the years they keep trying to take it from us, for whatever reasons, jealously or whatever, they open up other buildings around the country which always get closed down, but our own was still standing and still operative. In 2016 they took it away from us and gave it to palliative care. That started off the last campaign because we had to fight to get it back. That was when we had to go strong and then we won it back. December 2019 we officially won it back. All those years before then [i.e. before 2016] we had everything in place."
> Interview with AA, dated 21 February 2024

During this interregnum period of the George Marsh Centre, it was asserted that it was not being used enough and hence had to be used for other purposes across secondary and tertiary care. This resulted in a lot of discontent among Haringey and North London sickle cell warriors.

When asked about centres like the George Marsh Centre in supporting people with sickle cell and maximising the centre as a space for tangible pastoral care for people living with sickle cell, the clinician stated:

> "I think, with the George Marsh [Centre], what we've done at the moment is put therapies over there and therapy go[es] hand-in-hand with physical. So if you look… these are the community staff who are going to be based at George Marsh very shortly. Then we're going to get the team of those nurses to start mobilising the patients to use it more. At the moment, it's been set-up, it's supposed to be a therapy centre, but there's nobody there overseeing it… there's even going to be a Service Manager who is going to oversee of all that, we can then start to engage more with the community, which is my passion. I believe you can only develop services if you know what the people actually want. So once we set-up we going to start to do some community projects with the users."
> Interview with BB, dated 16 January 2024

It is now however, in word and action, evident that not only has sickle cell in recent years been regarded as a low priority but also that it took a tragedy in North London for there be any solid realisation that sickle cell in the area must be afforded due attention. One participant suggested that there could be better use of the building and that there could be:

- Better use of assisted technologies.
- tech to help people.
- supporting people in their career guidance.
- more activities for children.
- more computers.

- better holistic and complimentary care such as acupuncture, massage, aromatherapy etc.
- workshops on medication.

There are more activities at the George Marsh Centre at present which utilise complementary therapies. A participant also suggested that there could be a home care service, where nurses would come out and give painkilling injections. This would keep people out of A&E, yet the participant suggested that this was in place, but the NHS became worried about addiction and hence stopped this service in 2023.

Another participant expressed the importance of being empowered to have one's voice heard when it came to concerns in secondary care:

> "This is what the system is designed to do, to make you feel like you can't complain, and to make you feel like when you do complain, things only get worse. And that needs to be fixed."
> Interview with EE, dated 25 February 2024

The new consultant haematologist whom we spoke to revealed the challenges for North Mid Hospital and the lack of progress over the last two decades:

> "I think North London is 20 years behind, with East London which is quite developed early on in the 2000s. When I first started working at North Mid it reminded me of Newham 20 years ago. The demographics are quite similar and the number of people ethnicity wise are quite similar. So, I am not sure why this area is behind whereas in East London we had more projects, we had more patient interaction, we had more workshops, we designed services around the patients, we were more in touch with the adult social services and children social services. I think North London is way behind even in terms of clinical pathway and protocols as well."
> Interview with BB, dated 16 January 2024

Nutrition is important and this was raised by a participant who was also part of an organisation in North London which provides support to people with sickle cell. The participant noted:

> "If you've got sickle cell it's very difficult to cook for yourself every day, that's why it's important to have some kind of support. When we go to visit people in hospital, we bring in food. When they come out of hospital we'll take cooked food to them. Because it's very easy to order in takeaway when you have sickle cell because you're hungry, you're in pain, you can't be around the kitchen cooking, so support is needed. Surround yourself with fresh foods so when you're hungry it's easy to snack, rather than pull out a biscuit and stuff which is not helping you, it's making you worse."
> Interview with AA, dated 21 February 2024

The ability of people with sickle cell to have agency is important, as the lack of control over the frequency of crises can lead to hopelessness and depression (Falvo, 2005: 243). A participant revealed:

> "Living with the condition is a challenge, but it's the only life I know. So there's nothing for me to compare it to apart from how I see the lives of other people, and seeing their vibrancy every day and being able to do things that I find myself wanting to do but can't finish unless I have assistance.."
> Interview with AA, dated 21 February 2024

In terms of negative experiences with secondary healthcare and medicalisation of black people as a result of sickle cell, distrust among sickle cell patients of healthcare services based on past and historic interactions means that many people with sickle cell will be cynical and sceptical of new interventions.

Previous experiences with experimentation later led people to be sceptical during the pandemic:

> "We were fighting for our centre which was built for us for years and then we won the right back for our centre, as it should have been...in 2019. Then COVID hit. Before this, they were saying that sickle cell isn't a disability, blah blah blah and we had to do years of fighting for our centre. Then COVID hit and then when they decided that they were going to start giving out the vaccinations, I use that word because that's the word they used for it, who's at the top of the board? Sickle cell patients! But yet, two weeks ago, we don't have a disability or a condition, now we are the most vulnerable? Us and the elderly."
> Interview with AA, dated 21 February 2024

There was a sense with this participant that there was no previous attention given to the health of sickle cell people prior:

> "The big drive that all sickle cell patients should get vaccinated asap, a minute ago we didn't even have a condition?! Then all of a sudden we the most vulnerable in the UK!"
> Interview with AA, dated 21 February 2024

Treatments which sickle patients do find of use, can also be abruptly axed with little consultation or discussion with people who have the condition. This was seen in January 2024 when a new drug, Crizanlizumab, that was previously approved treat sickle cell and rolled out in 2022 was axed by the Medicines and Healthcare Products Regulatory Agency (MHRA), a part of the Department of Health and Social Care.

Furthermore, psycho-social support must also be addressed for people with sickle cell disease. The consultant haematologist we spoke to highlighted,

> "What happens with sickle cell is that because it affects the red cells, the haemoglobin is the one that carries the oxygen around the body, so when a sickle cell person is distressed, or they're going through stress, anxiety or depression, they also go into a physical crisis. So if we do not sort [out] the emotional wellbeing, it can actually affect the physical as well."
> Interview with BB, dated 16 January 2024

# Conclusion

Both the NHS in the 1950s and the welfare state system in the UK were inextricably linked to colonialism and hence were conceptualised, by some politicians such as Enoch Powell, as being the twin rewards for white Britons for what had been endured during the Second World War. Hence, the welfare system did exclude black and Asian people from the colonies for many years as they were not deemed as entitled. Similarly, access to healthcare within the NHS for conditions which were largely seen among minoritised communities was given scant priority.

The NHS was therefore conceived as a health system to maintain the health of a white imperial nation, while black people were viewed as social problems and this served to render the concerns of black people as invisible. This is even though in 1968 commonwealth migrants from the colonies comprised 30% of nurse student vacancies and 29% of student midwives in the NHS. During the period of decolonisation then, the NHS was staffed by migrant labour.

The health system was not set-up to prioritise the health of black people, yet it was staffed by black nurses and doctors from the colonies who witnessed racism on a daily basis. They were able to bring to the fore conditions such as sickle cell and effect system change, thereby challenging the treatment of black patients within the NHS.

When a condition is given scant attention, it leads to minimising the needs of people with that condition, as is seen with sickle cell in the United Kingdom. Hence, it was not until the medical and health activism of individuals such as Neville Clare, nurse Elizabeth Anionwu and the Brent Community Health Council that sickle cell began to be taken more seriously by the NHS. Local health authorities throughout the 1970s and 80s therefore deemed people with sickle cell trait and disease as a socio-cultural-geo minority and therefore not worthy of significant public health intervention.

However, hyper local healthcare professionals at the time worked within their budgets, sometimes on a voluntary basis, to run pilot screening programmes. Since then, national newborn screening in England has increased the number of children identified with sickle cell disease and trait.

The welfare system has only recently begun to take serious action on ensuring that people with sickle cell disease can access the support they need. There is now improved monitoring of the condition, better equipment within North Middlesex Hospital, better treatments and an increased incorporation of psychosocial models

of health across North Central London as evidenced with the new Community Red Cell Service for adults with SCD. Psycho-social risk factors include social support, control and autonomy at work, home/life balance. People who have good relationships with family and friends, and who participate in their communities have been shown to have longer life expectancies than those who are isolated.

The conventional biomedical model, with its focus on the clinical physical manifestations of sickle cell, overlooks psycho-social risk factors which may lead to frequent hospitalisations, morbidity and mortality. Poor social conditions produce a physiological stress response which exacerbates poor physical health, and as a result must be addressed. Included in this are ensuring access to benefits which people with sickle cell are eligible to receive, and career support while navigating employment with the condition.

Moreover, sickle cell centres, such as the George Marsh Centre, which have a focus on disease management may also lead to better quality of life for people with sickle cell (Khan et al., 2023).

# Bibliography


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

Atkin, K. and Ahmed, W.I.U. (2000). "Family Caregiving and Chronic Illness: How parents cope with a child with sickle cell disorder or thalassemia." Health and Social Care in the Community, 8(1), 57-69.

Bediako, S.M., Lanzkron, S., Diener-West, M., Onojobi, G., Beach, M.C., Haywood, C. Jr. (2016). "The Measure of Sickle Cell Stigma: Initial findings from the Improving Patient Outcomes through Respect and Trust study." Journal of Health Psychology, 21(5), 808–820.

Bediako, S.M. (2010). "Predictors of Employment Status Among African Americans with Sickle Cell Disease." Journal of Health Care for the Poor and Underserved, 21(4), 1124–1137. Accessed Online May 2024: https://www.researchgate.net/publication/49630179_Predictors_of_Employment_Status_among_African_Americans_with_Sickle_Cell_Disease

Black, S. and Laws, J. (1986). Living with Sickle Cell Disease: An Enquiry into the Need for Health and Social Service Provision for Sickle Cell Sufferers in Newham. London: East London Branch of the Sickle Cell Society.

Bryan, B., Dadzie, S. and Scafe, S. (1985). The Heart of Race: Black Women's Lives in Britain. London: Virago.

Carlson, R., Duff, M.C., Flake, D.F. and Bales, R.A. (2023). Employment Law. New York, NY: Aspen.

Cashmore, E. (2004). Encyclopedia of Race and Ethnic Studies. London: Routledge.

Chouhan, L. and Nazroo, J. (2020). "Health Inequalities." Bridget Byrne, Claire Alexander, Omar Khan, James Nazroo and William Shankley (eds.), Ethnicity and Race in the UK: State of the Nation. Bristol: Policy Press. 73-93.

Clare, N. (2007). An Oscar for My Troubles: A Life Working for Better Understanding and Treatment of Sickle Cell Disorder. Enstone: Writersworld.

Craig, C.E. (2009). Basic Labor and Employment Law for Paralegals. New York, NY: Aspen Publishers.

Crown, H. (2010). "Sickle cell anaemia campaigner is a real 'treasure'." Enfield

Independent, 20th January 2010. Accessed Online May 2024: https://www.enfieldindependent.co.uk/news/4862420.sickle-cell-anaemia-campaigner-is-a-real-treasure/

Dyson, S. (2016). Sickle Cell and the Social Sciences: Health, Racism and Disablement. Abingdon, Oxon: Routledge.

Dyson, S.M., Atkin, K.M., Berghs, M.J. and Green, A.M. (2021). "On the Possibility of a Disabled Life in Capitalist Ruins: Black workers with sickle cell disorder in England." Social Science and Medicine, 272. Accessed Online May 2024: https://www.sciencedirect.com/science/article/abs/pii/S0277953621000459

Falvo, D.R. (2005). Medical and Psychosocial Aspects of Chronic Illness and Disability. Sudbury, MA: Jones and Bartlett Publishers.

Filipp, M. (2008). The Practical Guide to Employment. New York, NY: Aspen Publishers.

Haywood, C. Jr., Diener-West, M., Strouse, J., et al. (2014). "Perceived discrimination in health care is associated with a greater burden of pain in sickle cell disease." Journal of Pain Symptom Management, 48(5), 934–943.

Howard, J. and Tefler, P. (2015). Sickle Cell Disease in Clinical Practice. London: Springer.

Khan, H., Krull, M., Hankins, J.S., Wang, W.C. and Porter, J.S. (2023). "Sickle Cell Disease and Social Determinants of Health: A Scoping Review." Pediatric Blood and Cancer, 70(2), Accessed Online May 2024: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9790038/

Koromoa, J. (2014). Sickle Cell: Simply Explained. Bloomington, IN: AuthorHouse.

Macdonald, J.J. (1992). Primary Health Care: Medicine in Its Place. Abingdon, Oxon and New York, NY: Earthscan.

Oni, L. (2023). "A History of Sickle Cell Disease and Race in the NHS." Royal College of Nurses Youtube channel. Accessed Online: May 2024.

Prashar, U., Anionwu, E. and Brozović, M. (1985). Sickle Cell Anaemia: Who Cares? A survey of screening and counselling facilities in England. London: The Runnymeade Trust.

Redhead, G. (2020). "The doctors who time forgot: Neville Clare, 1946-2015." British Medical Journal, 14 December 2020.

(2021). "'A British Problem Affecting British People': Sickle Cell Anaemia, Medical

Activism and Race in the National Health Service, 1975-1993." Twentieth Century British History, 32(2), 189-211. Accessed Online May 2024: https://academic.oup.com/tcbh/article/32/2/189/6324150

Medical Activism and Race in the National Health Service, 1975-1993." Twentieth Century British History, 32(2), 189-211. Accessed Online May 2024: https://academic.oup.com/tcbh/article/32/2/189/6324150

(2023). "A History of Sickle Cell Disease and Race in the NHS." Royal College of Nurses Youtube channel. Accessed Online: May 2024.

Rouse, C.M. (2009). Uncertain Suffering: Racial Health Care Disparities and Sickle Cell Disease. London: University of California Press.

Stanton, M.V., Jonassaint, C.R., Bartholomew, F.B., et al. (2010). "The association of optimism and perceived discrimination with health care utilization in adults with sickle cell disease." Journal of National Medical Association, 102(11), 1056–1063.

Williams, C. and Johnson, M.R.D. (2010). Race and Ethnicity in a Welfare Society. Maidenhead: Open University Press.

Williams, H., Silva, R.N.S., Cline, D., Freiermuth, C., Tanabe, P. (2018). "Social and Behavioral Factors in Sickle Cell Disease: Employment Predicts Decreased Health Care Utilization." Journal of Health Care for the Poor and Underserved, 29(2), 814–829.

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