Histories of sickle cell anaemia in postcolonial Britain, 1948-1997

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I, Grace Olivia Redhead, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.
Abstract

This thesis examines the interactions between post-war immigration, the welfare state and ideas of belonging and citizenship in Britain, focusing on the hereditary blood condition sickle cell anaemia (SCA). By following SCA through five different spheres – those living with the illness, doctors and nurses ‘on the ground’ in the National Health Service’s hospitals and surgeries, medical researchers at the cutting edge of molecular biology, patient advocacy groups and policymakers in Whitehall – this thesis reconstructs an architecture of state power and political protest, and traces changing ideas of British citizenship and ‘race’ across the post-war period. Using oral histories, archival research and data analysis, this thesis is in the format of cross-section of the institutions and communities who encountered the condition across a sixty-year period. Drawing on a range of sources, including government papers, medical journals, laboratory casebooks, memoirs and oral histories, this thesis is both a case study in the shifting power of patients and patient groups within the NHS, and of the impact of protest, advocacy and Black British political action in reconfiguring notions of citizenship and shaping the priorities of the British state. Recent historiography has uncovered the influence of decolonization and Commonwealth migration upon the emergent British welfare state in this period, and this thesis draws connections between anthropology, colonial medicine and the experiences of Black British people in the clinics and wards of the National Health Service. It illustrates how Black healthcare professionals shaped the NHS and challenged institutional racism through often unpaid or unstable work. The project speaks to a rich historiography dealing with agency in the relationship between non-white communities in Britain and the British state, in terms of how racism is constituted in public life, how institutional racism operates and is challenged, and how ethnocentric definitions of citizenship are contested or reinforced. This thesis makes the case that the experiences of people with SCA have been tied to the position of Black British voices within the NHS and in the British political system, and the example of SCA is a compelling historic case for diversity in these institutions.
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# Table of Contents

**Abstract**

**Acknowledgements**

**List of figures**

**Introduction**

**Chapter 1: The ‘great British haemoglobin king’: Race, migration and postcolonial genetic research in the clinic and the field, 1953-1985**

**Chapter 2: From Whitehall to West Bromwich: Sickle cell policy and funding in central and local government, 1968-1993**

**Chapter 3: Seeing like a welfare state: Race, visibility and legitimacy in NHS sickle cell services, 1973-1997**

**Chapter 4: Between hospital and community: grassroots sickle cell activism, 1974-1997**

**Chapter 5: Embodied citizenship: Patient experiences and narratives of sickle cell disease**

**Conclusion**

**Bibliography**
List of figures

Table 1: List of categories for MRCAHU blood sample origin descriptors (p.63)

Chart 1: Origins description data and contextualisation (p.64)

Chart 2: Distribution of origin description ‘types’, % (p.64)

Table 2: Ten countries with the most blood consignment during sample years (excluding UK) (p.78)

Figure 1: Still from *Sickle Cell Anaemia in Nigeria*, prod. Ralph Hendrickse (London: The Royal Anthropological Institute, 1964). (p.133)

Figure 2: From L R Davis, E R Huehns, and M White, ‘Survey of Sickle-Cell Disease in England and Wales’, *British Medical Journal* 283 (1981): 1520. (p.137)

Table 3: Sickle Cell Society Committee gender breakdown 1982-1998 (p.175)

Figure 3: Sickle Cell Society logo, 1982-90. Sickle Cell Society Archive (uncatalogued). (p.190)

Figure 4: Sickle Cell Society logo, 1990 onwards, Sickle Cell Society Archive. (p.190)


Figure 7: Donald Rodney, *Britannia Hospital III* (1988) oil pastel on X-ray © The Estate of Donald Rodney, Courtesy Museums Sheffield. (p.232)

Figure 8: Donald Rodney, *Visceral Canker* (1 panel, 1990), Perspex, wood, silicon tubing, gold leaf, plastic bags and electrical pump © The Estate of Donald Rodney, Courtesy Tate Britain. (p.236)

Figure 9: Donald Rodney, *Flesh of My Flesh* (1996) photograph on aluminium ©The Estate of Donald Rodney, Courtesy the South London Gallery. (p.238)
Introduction

In the 1995 film *Three Songs: Pain, Light and Time*, made by the Black Audio Film Collective, the artist Donald Rodney remembered a visit he once made to the Science Museum. There he had seen

in a display case a model of a haemoglobin cell, and on the side of the cabinet you could press a button and it lit up this tiny little light right at the back of the cell, which turned out to be the actual bit of the haemoglobin which caused sickle cell. It was very bizarre seeing the cause of the pain being that small and being that insignificant.¹

This display was part of the *Living Molecules* exhibition staged in the Science Museum in 1987, dedicated to celebrating forty years of research at the Laboratory of Molecular Biology in Cambridge. It featured molecular models built by scientists such as Max Perutz and John Kendrew during the 1950s explosion in molecular genetics.² The touch of a button illuminated the position of the single amino acid change that characterises sickle cell anaemia (SCA), a mutation first described in 1957.³ For these scientists, SCA offered a new paradigm – the first time a disease could be directly linked to a DNA alteration. This condition, however, held a very different meaning for Rodney. Born ten years after Neel’s discovery, he had lived with sickle cell disease (SCD) all his life. It had entailed hospitalisation and increasingly limited mobility, pain and late-night ambulances, operations and recuperating on the ward with a sketchbook. Unable to play sports as a child, he took up painting and drawing, and in his career as an artist his illness both limited him and became one of his most fruitful subjects. Perutz’s haemoglobin model was displayed

to celebrate scientific achievement, and as Rodney looked at it he marvelled at how ‘small’ and ‘insignificant’ the cause of his pain was. For all the simplicity of the sickle cell mutation, and the complexity of its discovery, and though for a time sickle cell had been, on a molecular level, the best-understood disease in the world, in 1987 this offered Rodney no therapy.

Rodney’s encounter with the haemoglobin model is characteristic of the ‘diagnostic-therapeutic gap’ between molecular genetics and clinical genetics in the twentieth century, in which people with genetic conditions often lived in the space between scientific understanding and therapeutic response. It also speaks to the different meanings that sickle cell anaemia (SCA) held in post-war Britain. Under the microscope in a Cambridge laboratory in the 1950s, it was the subject of elite, transnational, paradigm-shifting research; for the young black artist on a trip to the Science Museum in London thirty years later, it was an invisible pain that defied description. This dissertation will draw out the divergent experiences and discourses about SCA in post-war Britain, and present SCA as a site of postcolonial encounter. Max Perutz’s haemoglobin model, constructed partly with reference to the sickle cell gene, is a product of the gaze of mid-twentieth century biochemistry and genetic science, which saw black bodies as research subjects through which ‘race’ could be scientifically explored. This gaze was returned, as Rodney’s story illustrates, by those who lived with the illness. Rodney documented his experiences of life with SCD in and out of hospital wards, through sketches, photographs and notes, and observed the work of those who studied his illness. The politics of health, race, migration and Black British resistance collided in these encounters.

A hereditary blood disorder, SCA is the result of a mutation of a single molecule on the haemoglobin gene, which causes the production of red blood cells which can assume an abnormal, rigid ‘sickle’ shape, impeding their passage through veins, causing ischaemia, heart attacks, strokes and pain. One copy of the trait confers resistance to malaria, and it therefore often occurs in people descended from

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5 I follow Melbourne Tapper in referring to sickle cell anaemia as an umbrella term for both the trait and disease. I will specify when I am referring particularly to either sickle cell disease (SCD) or the sickle cell trait. See Melbourne Tapper, ‘Interrogating Bodies: Medico-Racial Knowledge, Politics, and the Study of a Disease’, *Comparative Studies in Society and History* 37:1 (1995): 76–93.
regions where malaria is or was common—such as sub-Saharan Africa, India, the Middle East and the Mediterranean. Two copies of the trait lead to a condition known as sickle cell disease. Despite its incidence across the world, SCA has nevertheless been racialized as a condition primarily affecting black people since its first observation in Western medicine.

From 1948 onwards, SCA shifted from its position in Britain as an obscure tropical disease known only to haematologists to, in the early 1990s, a high-profile genetic disease, a rallying point for black activists, and a government health priority. In postcolonial Britain, SCA was embedded in discourses about race relations, scientific race theory, the politics of health, genetics, the role of national and local government, citizenship, Black Power and migration. It functioned differently within these discourses: as a contested marker of race, both a political threat and opportunity for the state, a medical discovery through which careers and institutions were made, and a symbol of institutional racism. This dissertation traces these multiple and shifting meanings across five different spheres: biochemical laboratories in Cambridge and connected with scientists and medical practitioners across the world, the offices of the Department of Health and Social Services in Whitehall, the hospital wards of the National Health Service, the headquarters of activist groups such as the Sickle Cell Society, and the homes of those living with the disease. In doing so, it maps the discourses in operation around ‘race’, citizenship, migration and health in post-war Britain. It finds that the welfare state, at every level, tacitly denied the full entitlements of British citizenship to Black Britons, and that Black Britons reconfigured ethnocentric notions of citizenship by demanding care and developing policy within the institutions of the welfare state.

The history of the condition in its present ontological incarnation as ‘sickle cell anaemia’ began in 1910, when ‘sickle-shaped corpuscles’ were observed in the blood of a young Grenadian dental student named Clement Noel at Presbyterian

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6 Although it is commonly stated that the sickle cell trait is asymptomatic, some literature does suggest that people with the sickle cell trait can experience symptoms such as chronic anaemia, or symptoms mimicking the disease under general anaesthetic, at high altitudes, strenuous exercise, dehydration or during pregnancy. See Mary Beth Seegars and Allan S. Brett, ‘Splenic infarction associated with sickle cell trait at low altitude’, Hematology 20:10 (2015): 607-609; Louis W Sullivan, ‘The Risks of Sickle-Cell Trait’, The New England Journal of Medicine, 317:13 (1987): 830-831.

7 Tapper, ‘Interrogating Bodies’, 80.
Hospital in Chicago. However, understandings of the illness have existed in African cultures for centuries. The Ghanaian physician Felix Konotey-Ahulu suggests that the diseases named Chwechweechwe, Nwiiwii, Nuiduidui, and Ahatutuo all reflect the ‘onomatopoeia of the repetitive gnawing pains characteristic of the sickle cell crisis’. It has been suggested that in Nigeria the myths of Ogbanje among the Ibo tribe and of Abiku in the Yoruba tribe, which tell of sickly children who die young and are endlessly reincarnated, describe the occurrence of SCA within families. Archaeological evidence of sickle cell trait or disease has been found in human remains in Egypt and Kuwait, in the former case dating back to 3200 BCE. The only ‘archive’ that claims to reveal a longer history of SCA is that of the human genome. In 2018 researchers at the National Human Genome Research Institute in the United States concluded, after analysis of sequenced genomes of 156 sickle cell carriers, that the sickle cell allele arose in a single individual 7,300 years ago in either the Sahara or west-central Africa, and that within 2,400 years the trait frequency within the population had increased to 12% as a result of the selective pressure of malaria. Like any other archive, however, the human genome only answers the questions that researchers come to ask of it.

In the last two decades, historians and social scientists have turned to SCA to explore what it can tell us about the politics of race, medicine and health in Britain and the United States. In his 2001 book Dying in the City of the Blues: Sickle Cell Anemia and the Politics of Race and Health, Keith Wailoo examined the first efforts to formulate health policy and treatment on SCA in the United States, focusing on the city of Memphis as a microcosm through which he explored transformations in

American health care, medical research and race politics in the twentieth century. He showed that SCA was mostly invisible in the first half of the century, hidden among the other health problems caused by sanitation issues and infectious diseases in the poverty of many communities in the southern United States in the 1930s and 1940s, along with a racist stereotype of black people as a ‘naturally diseased people’. As sanitation improved and the disease became more clinically visible, it was increasingly seen as a ‘cutting-edge scientific puzzle’, and people with the malady as ‘important research opportunities’. As the healthcare institutions of Memphis began to desegregate in the 1960s, they leveraged SCA as a ‘commodity’ to gain federal funding to research and treat it, and sickle cell became increasingly useful ‘in raising community consciousness, in mobilizing resources, in building institutions, and in creating research programs’. In the 1970s, mainstream American politics and media embraced SCD as an issue, and Richard Nixon proposed the National Sickle Cell Anaemia Control Act. However, the discourse around the illness had focused into what Wailoo calls ‘inferiority debates’, used by some to make the case for ‘the existence of biological racial differences’, while some black communities feared screening and genetic counselling as ‘black genocide’. The increasing conservatism of the 1980s and 1990s shifted medical sympathy for sickle cell pain, which had been rooted in the 1970s in notions of ‘restorative justice’, towards skepticism of the credibility of SCD pain and fears of narcotic addiction.

Melbourne Tapper explored how scientific and medical research into SCA framed race and ethnicity as objective facts, in In the Blood: Sickle Cell Anaemia and the Politics of Race, his 1999 study of discourse around the disease between the 1920s and the 1980s in the United States and colonial Africa. Initially framed as a ‘black disease’ in the 1920s and 1930s in the United States, it was seen as distinctive to the ‘American Negro’ despite strong evidence that it could be found in white people. Over time it was reframed by the medical profession as a disease of racial ‘miscegenation’. In colonial Africa in the 1950s, researchers used the sickle

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13 Wailoo, Dying in the City of the Blues, 12.
14 Ibid, 56.
15 Ibid, 106, 117.
16 Ibid, 128.
17 Ibid, 187.
18 Ibid, 205.
cell trait to classify and naturalize tribal divisions. Even after the supposed break that genetics was supposed to represent from eugenics and scientific racism after 1945, genetic testing in colonial Africa in the 1950s continued to engage with discourses of scientific racism dating back to the nineteenth century. Finally, Tapper shows that the link between black bodies and sickling risk was considered to be so strong that government action on SCA in the 1970s could be tied to a post-civil rights discourse of African American citizenship.

Both Wailoo and Tapper closely focus on the United States. Where Tapper turns to colonial scientists, he does not contextualize their work within post-war British decolonization and migration. Roberta Bivins has examined the profile of SCA in post-war Britain in several publications, and offered an overview of SCA in Britain by bringing the approaches of New Imperial history to a National Health Service often uncritically left as a symbol of Britain’s post-war inclusivity and progressive thinking. She positions SCA in Britain as a case study of postcolonial medicine, in which a previously ‘tropical’ disease came ‘home’ to the metropole with migration to Britain from the Commonwealth, and argues that the UK’s ‘less toxic’ racial politics made SCA easier to treat within affected communities than in the US, although a rapid response was ultimately frustrated by a lack of political will. She discusses SCA alongside other racialized health conditions such as tuberculosis and rickets, and elucidates ‘a more complex genesis for health policy and responses than racial antagonism alone’.

Like Wailoo and Tapper, Bivins focuses primarily on the discourse around SCA in the circles of civil servants and medical professionals, with much analysis of the high-level policy discussions in the Department of Health and Social Services.

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21 Bivins, *Contagious Communities*, 307.

22 Ibid, 508.
(DHSS) and the Medical Research Council (MRC), which are a crucial element of NHS culture and action. However, as is frequently noted in DHSS and MRC memoranda throughout the period, they were reluctant to issue directives to the service – disavowing the responsibility of central government for the minutiae of policies around specific illnesses, especially ones that made specific demands of healthcare professionals. As Rudolf Klein has observed, a theme in the history of the NHS since its birth has been its cycle of experiments with centralization and delegation, and a tension between local health services’ accountability to local needs and Ministerial accountability to Parliament. This dissertation will reconstruct the full infrastructure of SCA policy and treatment in the period, and explore the role played by local developments in shaping national experiences and policies. The work done by consultants and nurses in hospital wards, health visitors and general practitioners in surgeries, community centres and homes, and advocacy groups in lobbying Local Health Authorities, is crucial to an account of conflict and change in sickle cell services. It will also seek to introduce the personal experiences of patients such as Rodney into the picture, historicizing patient experience of SCA in the post-war period. These perspectives show that change in SCA services was wrought by grassroots activists and local services, rather than Whitehall or the senior figures of the medical establishment.

In doing so, this dissertation draws on the work of sociologist Simon Dyson, whose research on the social and political aspects of sickle cell and thalassaemia (another haemoglobin disorder) in Britain and overseas has paid attention to the experiences of those living with the trait and disease, to the emerging professions of SCA and thalassaemia counsellors, and to the politics of support groups, community care and ‘race’ in Britain. By incorporating the local, the periphery and the patient into our view of SCA, this dissertation does two things. It shows that citizenship was contested and reconfigured within the Welfare State in the post-war period along the

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lines of ‘race’ and ethnicity, and that the infrastructure of the state – the Department of Health, Local Authorities, hospital wards and NGOs – operated to peripheralise issues of ethnic minority health. Through an in-depth ‘biography’ of SCA I uncover the strategies of delaying and distancing in Whitehall, and the work done to render SCA visible and manageable in clinics, councils and community centres. Dyson argues that the linking of haemoglobinopathies and ‘minority ethnic groups’ in Britain ‘has been politically important in drawing attention to inequities in service provision’ for Black British health concerns, whilst also problematizing the racialization of the condition in Britain as solely affecting African and Caribbean people. This dissertation follows this link in using SCA as a ‘tracer condition’ by which to explore both institutional neglect and anti-racist action in the welfare state, and exploring how SCA continues to be re-racialized. As Roger Cooter has noted in his discussion of biographies of illness, centring an illness in turn decentres the narratives of ‘great men’, hero doctors and pioneering institutions. This is not just a question of perspective, but has implications for uncovering the origins of historical change, causality and agency. By following action on SCA through the service – from patients, to advocates, to healthcare professionals, to NHS managers, to civil servants and Members of Parliament – it becomes clear that decision-making and influence within the NHS, particularly when it comes to the treatment of single diseases, was decentralized and diffused across these groups and sub-organisations. In her historical account, Bivins notes that action on SCA was stalled at the level of DHSS and the MRC, but this dissertation finds that in hospital wards and community organisations, haematologists, nurses, health visitors and paediatricians generated clinical consensus and political energy at a local level. Beyond questions of causality and agency, biographies of illness provide a vantage point onto how individuals conceive their identities, bodies and relationships, and reveals that SCA was a lens through which Black Britons, and particularly patients and families with SCA, perceived the welfare state and their relationship to it.

28 Bivins, Contagious Communities, 360.
This dissertation tracks SCA across a fifty-year time period, from 1948 to 1997. During the late 1940s and 1950s SCA was seen as an exciting tool for the investigation of human evolution and migration in Africa, and an opportunity to investigate human genetic diversity from the 1950s to the 1970s. From the late 1960s to the beginning of the 1980s, DHSS was increasingly consulted by doctors for government advice on how to deal with the charged question of screening immigrant children for a genetic disease. Meanwhile, local haematologists began to pilot screening and treatment programmes for the sickle cell patients in their service, and as part of the wider turn towards community politics challenging the bureaucracy of local government, health activists such as Protasia Torkington in Liverpool increasingly organized to bring these issues to the attention of local government. In the 1970s, the explosion of new left movements built around race and gender politics, including organisations such as the Organisation of Women of African and Asian Descent (OWAAD), in turn gave rise to groups such as Sickle Cell Society. The evidence submitted by these groups to the Select Committee on Home Affairs, following the 1980-81 uprisings in Brixton and Toxteth, reframed the government’s approach to the condition from something that should be avoided to a political tool that could be used to demonstrate the government’s commitment to ‘multiculturalism’ and ‘black self-help’. In the late 1980s and early 1990s, a new centring of the patient-consumer in the NHS structure (as in the 1991 Patient’s Charter) elevated the experiences of SCA patients to central government. This dissertation finishes in 1997, before the election of a New Labour government and its subsequent NHS reforms led to transformations in the health landscape. In addition to the specific historiography of SCA, this dissertation is situated in several bodies of literature, which I will now outline.

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Reconfiguring citizenship in the British Welfare State

This dissertation takes as its starting point the year 1948 – in which the National Health Service was established, the first health system in the West to offer free medical care to the entire population, and the first comprehensive system to be based on the national provision of services, rather than insurance.  

1948 was also the year of the British Nationality Act, which enshrined in law the long-held principle that everyone born within the British Empire and metropole had equal rights to British citizenship. The Act created, for a fifteen-year period, an equal citizenship status between the British residents of the metropole and 800 million colonial citizens. Earlier that year, the Empire Windrush docked at Tilbury from Jamaica, an event now considered to be the symbolic beginning of post-war immigration. This event was greeted by the government with dismay – the Ministry of Labour refused to arrange employment for the Jamaican arrivals, for fear of ‘encourag[ing] others’, and Prime Minister Clement Attlee told the Colonial Secretary to ensure that ‘further similar movements either from Jamaica or elsewhere in the Colonial Empire are detected and checked before they can reach such an embarrassing stage’. If citizenship for all was, in the corridors of power, a hollow concept from the beginning, would their entitlement to medical care prove equally hollow?

The starting point of 1948 is not intended as a reification of the notion that the Windrush was the ‘first arrival’ of Black people in Britain—an assumption which Caroline Bressey has described as ‘a divide claim[ing] a white and pleasant land of white British people that existed until the arrival as ships such as the Empire Windrush from the colonies in the 1950s and 1960s’. Works by Bressey and others have dealt significant blows to this myth of a ‘land of white British people’, uncovering the lives of Black men and women who lived in Britain from the sixteenth

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century onwards. This dissertation therefore focuses on a particular encounter in the relationship between the British state and its black metropolitan subjects, mediated through the post-war Welfare State. As Stuart Hall argued, ‘the type and scale of migration into Britain from the non-white global periphery, which has seriously challenged the settled notion of British identity and posed ‘the multi-cultural question’, is a post-Second World War, post-colonial, phenomenon’. If the Windrush is a watershed, it 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.

There has been extensive historiographical discussion of the relationship between the Welfare State and black settlers and their children, and we might summarise the discussion of this mutual influence into five key points. Firstly, Caribbean and Asian migrants have played a significant role in staffing the NHS since it first opened its doors, and this dissertation will join the work of Julian M. Simpson in showing that their employment has in turn shaped the nature of the service. Secondly, decolonization during the 1950s and 1960s influenced the welfare state’s nascent forms of assistance. Jordanna Bailkin has demonstrated the connections between the practice of early social services and the construction of West African and West Indian mothers as ‘unfit’, and finds that migration ‘was one of the first issues that postwar experts were called upon to manage and define’. Thirdly, as Camilla Schofield has shown in her study of late 1960s and early 1970s Powellism, the welfare state was understood as a reward for wartime sacrifice which was, in turn, ‘whitewashed’ by Enoch Powell and his supporters, erasing ‘the sacrifices of Britain’s non-white colonial forces’ and refusing their welfare entitlement. Fourthly, the progressive legal exclusion of Commonwealth migrants in

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the 1960s and 1970s, marked by increasingly restrictive Commonwealth Immigration Acts, was partially predicated on and fuelled by discourses of ‘welfare parasitism’, a fear that such migrants would exploit and overrun the Welfare State.40 Finally, as Paul Gilroy has observed, when British political regimes were ‘in flight from socialist principles and welfare state inclusivity’ particularly in the late 1970s and 1980s, they used notions of ‘strangers and aliens’ to measure the limit for welfare. These Windrush migrants and their children were forever seen as ‘immigrants’.41 This point has been illustrated by the Windrush scandal from 2018 onwards and the case of Sylvester Marshall, who – having arrived in the UK from Jamaica in 1973 and lived in the country for 44 years – was told that he had to pay for his radiotherapy ‘until he could prove he was eligible for free NHS care’.42

The nexus of this relationship between Windrush and welfare is the contested nature of non-white citizenship in post-war Britain, in which as Matthew Grant notes, ‘although non-white people may have had the status of formal citizens, they were not treated as such, politically or socially’.43 An examination of SCA in post-war Britain enables us to explore both the resultant direct discrimination in the restriction of welfare resources, and the resistance to this discrimination by Black British people, who articulated their citizenship and demanded that their rights be observed and protected. But let me be clear: opposition to funding for research into SCA or development of services for those with the condition was rarely overtly predicated on the notion that those affected by the condition – which was so closely associated with the Black community that it was virtually analogous – did not have British citizenship, and therefore did not have access to the resources and care of the British welfare state. The formal citizenship status of migrants from the Caribbean

and African countries was rarely questioned in discussions over SCA. Instead, their entitlement was informally contested through the inertia with which central government addressed SCA. A central challenge of this work has therefore been to unpick the reasons behind the neglect of SCA, both at the level of central resource allocation, and in individual clinical encounters.

Neglect and misunderstanding are common to the trajectories of many diseases, but this dissertation contends that in the case of SCA, this neglect and misunderstanding was uniquely racialized. The Liverpool health activist Protasia Torkington observed in 1991 when comparing the positions of PKU and SCA in respect to neonatal screening, structural inertia can only go so far to explain such discrepancies. ‘[R]acism is implicated even at this level of organizational change,’ she argued.44 This dissertation argues that the reasons for delay and avoidance ranged from the implications of focusing on a ‘racial’ disease, to conceptions of black communities as not amenable to healthcare intervention, to a sense that SCA and its sister condition thalassaemia should be tackled together with other genetic diseases (primarily affecting white people) which were less straightforward to test for, to the notion that SCA was an ‘urban’ disease that should instead receive local, rather than main programme, funding. These varied justifications for delay and delegation, rooted in an ethnocentric vision of health needs, financial priorities and ‘British’ people, served to erode the formal citizenship status of Black British communities.

This dissertation therefore examines the ways in which black citizens were disenfranchised in the health systems of the post-war period, but it will also explore this contestation of citizenship as a bottom-up as well as a top-down process. For several decades, studies of race politics in post-war Britain tended to focus on the anxiety and racism of Britain’s white population and state apparatus in response to the ‘arrival’ of New Commonwealth settlers.45 The work of policymakers and social scientists in researching and constructing these groups as ‘immigrants’ has been

studied in depth, and elicited powerful insights into the nature and function of British racism in the twentieth century – a process in which the state is heavily implicated. However, in these works Black and Asian people themselves have tended to recede into the background, figuring as the anxious projections of said policymakers rather than actors, appearing as passive ‘objects’ as opposed to active ‘subjects’. This veers dangerously close to what Gilroy has described as the ‘principle mechanism’ of racial thinking – the construction of Black people as either ‘problem’ or ‘victim’. The latter mode defines Black people as ‘beings that feel yet lack the ability to think, and remain incapable of considered behaviour in an active mode’.  

This has been countered, in the last two decades, by historical work documenting the agency of Black British people in reshaping the nation. Kennetta Hammond Perry’s *London Belongs to Me* shows that Black British activists were forefront in fracturing Britain’s self-perception as a tolerant nation, and invoking their citizenship ‘as a tool of claim making and a language of belonging’ for Black people in postcolonial Britain. Rob Waters has explored how global black resistance politics reconfigured British political discourses of race and processes of racialization through his explorations of publications such as *Race Today*, institutions such as the Runnymede Trust and television programmes which beamed coverage of US Black Power into British homes. Bill Schwarz’s work argues that the West Indian emigrant to Britain ‘became an important, if often reluctant, agent in imagining a future for Britain after colonialism’, for their position in the ‘mother country’ meant that in navigating their daily lives they continually negotiated the hierarchies and double standards of the colonizers. This dissertation aims to trace discourse and action on SCA across centralized state action, community activism and individual

experience. By following the condition through hospital wards, committee rooms, laboratories and community centres, we can reveal how ideologies of race and claims for citizenship made their way through the structures of the state in practice. It was in everyday experiences of health, illness and hospitalization, as well as in external organization and action, that SCD patients challenged medical stereotypes about Black people and ethnocentric concepts of citizenship by articulating their entitlement to care.

The establishment of the NHS is often seen as ‘the apogee of social citizenship’, reifying healthcare as a right, not a favour. Though the initial NHS Act of 1946 had been framed around the duty to provide services rather than the right of the patient to receive them, the status of patient as taxpayer was incorporated into a language of patient rights from the 1960s onwards, as Alex Mold has shown.\(^{51}\) However, this conception of social citizenship and health as a right began to be eroded in the 1970s by ascendant neoliberal ideas about health markets, and anxiety that the health behaviours of the individual were placing pressure on public finances.\(^{52}\) Though SCA is an inherited condition rather than one attributed to lifestyle, it was through this language of health citizenship that patient rights to SCA services were challenged, as the health of black families and their amenability to health intervention were called into question and authorities denied that sufficient numbers existed even in so-called ‘immigrant areas’ to justify the expense. With Black Britons often implicitly excluded from the notion of British citizenship, their status of health citizenship and their entitlement to health services was also challenged through this prism.

However, it was also through notions of health citizenship that Black British activists articulated their right to care. During the 1980s, the work of haematologists, nurses and community activists made the argument for patient-centred SCA care, focused on the rights of the sickle cell patient, on information and education about SCA, and on treating the individual patient as the expert on their condition, medical history and medication requirements. Florence Sutcliffe-Braithwaite has argued that

\(^{51}\) Mold, ‘Patient Groups and the Construction of the Patient-Consumer in Britain’, 511.
the individualism that has been associated with Thatcherism in Britain was actually emergent in the decades before, partly facilitated by political movements structured around identities such as gender, race and sexuality. Alex Mold too has shown that though individual choice in an NHS marketplace characterized Thatcherite health policy by the end of the 1980s, these arguments were being made by patient groups in the 1960s and 1970s who voiced the need for information, rights and choice on a collective as well as an individual basis. In the case of SCA health activism, which articulated a demand for sickle cell patients as a collective to receive a basic standard of care, the language of the patient-consumer served to challenge the systemic racism that had marked their treatment. In what Mold has described as ‘the critical moment in the remaking of the relationship between the state and citizen in Britain, as the supposed consensus around universal entitlements to welfare was eroded by the concept of individualistic rights to, and choice of, services’, SCA is a case study in which this entitlement appeared particularly hollow, and in which a rhetoric of individualism and choice was a promising route to resolution. SCA organisations formed part of a broader rise of national health pressure groups such as Action on Smoking and Health, who Virginia Berridge argues were ‘part of an essential policy-balancing act for government’. Almost at the same time as SCA entered the public consciousness, in the 1980s, another condition which also affected a marginalized community, and also was for the most part ignored and misunderstood by the state and medical establishments, was coming to prominence – AIDS. Berridge found that the first phase in the development of a clinical and policy response to AIDS in Britain was a period of ‘policy-making from below’, drawing on the expertise of outsiders and an ethos of ‘self-help’ within the gay community, followed by an ‘intense period of wartime crisis’, replaced in the late 1980s and 1990s ‘by talk of normalization and chronic disease’. Such marginalized groups had to address the contradiction faced by many voluntary sector organizations,

55 Ibid, 510.
57 Ibid, 281.
whether ‘potential co-operation with the state [would] actually mean potential co-option and incorporation? Would community organizations simply come to do the bidding of the state?’

‘Race’, racism and anti-racism in post-war British science and society

Michelle Brattain has criticized many historical considerations of political and cultural practices of racism for failing to examine

the historical nature of the race concept(s) that gave these particular practices their form… In other words, while we know that races mattered, we seldom ask what historical actors believed race was, and how that notion permitted racist practices. This is especially true in the history of the late twentieth century, when ideas about human variation more closely resembled those common today. But simply documenting archaic uses of race does not represent a full embrace of the implications of thinking of race as a social construction unless we also consider, carefully and critically, the implications of how we treat race in our own historical work.

This dissertation seeks to identify what various actors considered to be ‘race’ in this period – and argues that historicizing both ‘race’ and racism in this period can help to identify how these notions permitted racist practices. During the twentieth century, racism became a politically damaging label both in science and in government, and can be seen to influence many of the decisions made regarding SCD policy and knowledge construction. However, ideas about what constituted both ‘race’ and racism shifted considerably across the period, enabling the reconstitution of ‘[b]iological racism and cultural differentialism’, which as Stuart Hall argued, ‘constitute not two different systems, but racism’s two registers’. We might assume

58 Ibid, 22.
60 Hall, ‘The Multi-Cultural Question’, 222.
that the discussion of SCA, as a genetic disease, would have been almost uniquely suited to the scientific register, but this dissertation will show how easily actors slipped between cultural and scientific keys when discussing it.

As Gavin Schaffer has noted, anti-racial agendas in British science date back to before the Second World War, exemplified in the seminal text *We Europeans*, which rejected the term ‘race’. The American anthropologist Ashley Montagu argued in the 1940s that examining the human genotype revealed that ‘race’ traits made up ‘probably no more than one per cent’ of human genetic material, and circulated his views in a popular volume entitled *Man’s Most Dangerous Myth*. This thinking about ‘race’ was closely connected to the discipline of eugenics, an epistemic framework of population improvement through selective breeding. Eugenics began to receive criticism in Britain and the United States during the inter-war period for the way many used the discipline to justify class and race hierarchy. When the Nazi regime in 1939-1945 employed eugenics to rationalize the genocide of millions of Jewish people and others under the banner of ‘racial hygiene’, a rejection of racism became deeply tied to a rejection of eugenics. As such, racism in scientific research was understood to be a question of methodology: of typological thinking, in which humans were separated into groups and their characteristics accorded a genetic superiority or inferiority. This enabled scientists to continue investigating human difference, with the concept of ‘race’ now framed through population thinking, in which humankind consists of ‘polymorphic populations made up of unique individuals’. Scientific conceptions of ‘race’ were not ‘in retreat’ in the decades following the Second World War. Scientists ‘proved unwilling to question the validity of race as a natural category’ into the 1960s and beyond. In this

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64 Ramsden, ‘Confronting the Stigma of Eugenics’, 856.
66 Brattain, ‘Race, Racism and Antiracism’, 1388.
context, the investigation of SCA was a promising research opportunity. In the first half of the twentieth century, SCA was initially understood as a trait found only in people of African descent. Further investigation during the 1950s and 1960s revealed it, and other haemoglobin variants, could be found in populations from south Asia, the Mediterranean and the Middle East. In this context, SCA had ambiguous implications for the study of human difference: biochemists and anthropologists were excited by what they saw as its potential to both render ‘race’ at a molecular level, and to make a point about the plasticity of genetic characteristics that disproved concepts of concrete racial difference.

A study of SCA allows us to trace the contact, exchange and conflict in definitions of race predicated on both biology and culture in post-war Britain. Scientists sought to make sense of SCA in a discipline made possible by fieldwork in former colonies, frequently staffed by former Colonial Medical Officers. They struggled to navigate academic communities fractured by the fallout from the Holocaust, as scholars who promoted biological determinism and hierarchy were pushed from the centre to the margins of bioscience. To make sense of the occurrence of SCA in various populations, scientists sometimes relied on the individual’s appearance and their correspondence to certain racial types was a central method of the research framing, reifying concrete notions of racial difference, stabilizing racial groups within a geography and time period, and ultimately substituting the term ‘populations’ for ‘races’.

As this dissertation will discuss, race was a toxic subject for the British state, and its officials sought to avoid accusations of racism particularly during the Second World War and decolonisation. In seeking to avoid accusations of racism, state actors sought to obscure the paradox at the heart of British racism – in which an ethnocentric vision of the British nation was placed in uncomfortable dialogue with its understanding of itself and its history as a liberal and benevolent imperial power. During the 1960s, Harold Wilson’s government undertook a two-pronged strategy in regard to race and immigration: successive Commonwealth Immigration Acts in 1962 and 1968 which functioned to restrict the citizenship and residency of non-white people, and the 1968 Race Relations Act which criminalized colour bars in housing,
employment and public services. In the late 1970s, ‘racial disadvantage’ became increasingly understood as a responsibility of the state, which responded with short-term funding for ‘self-help’ ethnic minority groups and public services in diverse areas, and into the 1990s the critique of ‘institutional racism’ increasingly gained traction. Using SCA as a case study, this thesis will outline a shift in the conceptions of ‘race’ and racism within the institutions of the British state. DHSS was reluctant to recommend screening of Black communities in Britain for fear of accusations of ‘eugenic’ thinking. Winston James and Clive Harris have argued that as biological notions of ‘race’ were refused as unacceptable, the term ‘race’ was increasingly excluded from public discussions in favour of ‘culture’ and ‘ethnicity’ during the late 1970s, serving to naturalize difference nearly as completely as the definitions they replaced. Such cultural assumptions about race also impeded state and medical action on SCA, through the mobilization of stereotypes about how cultural or ethnic background influenced the expression of pain, and suggestions within medical journals that the structure of African and Caribbean families made them unsuitable for genetic intervention. Troy Duster has argued that the dichotomy between ‘race as biological’ and ‘race as merely a social construction’ has actually enabled states, health services and pharmaceutical companies to obscure the medical needs of its citizens, enabling them to deny that health inequalities exist and to impose one-size-fits-all treatments and medications (which have often been tested on white bodies) upon people for whom they are unsuited. This dissertation shows that patient groups such as the Sickle Cell Society (SCS) and the Organisation for Sickle Cell Anaemia Research (OSCAR) recruited biological conceptions of ‘race’ into an anti-racist rhetoric, as they leaned into the link between SCA and African and Caribbean populations to demand treatment, used it as a tracer condition by which NHS approaches to black communities could be appraised, and rejected the tropes of cultural racism by which the state absolved itself of responsibility.

67 Perry, London is the Place for Me, 217-8.
As the chapters that follow demonstrate, state reluctance was only overcome by the alternative definition of ‘race’ that entered the mainstream in the 1980s – that ‘race’ was given meaning not by biology but by historic discrimination – and by increasingly assertive community expressions of pride in black identities, and demands for SCA treatment and screening. Once critiques of ‘institutional racism’ were in the ascendant in the mid-1980s, aversion to targeting black people for genetic screening was replaced by an awareness that not doing so could be perceived as discrimination through neglect. This dissertation therefore makes the case that notions of ‘race’, racism and anti-racism were in dialogue with one another in this period, and served to both enable and challenge discrimination within the NHS.

Just as this dissertation explores the ways in which the state and the NHS upheld and perpetuated racial inequality through notions of racial difference and ethnocentric citizenship, it also observes efforts at anti-racist education within the NHS and adjacent institutions. Efforts to confront implicit biases can be seen in Whitehall discussions over resource allocation, in doctor-patient encounters, and in medical research. Nurses and health visitors who worked in sickle cell units ran workshops for nurses and doctors on hospital wards to counter racial stereotyping in clinical decision-making; civil servants upbraided each other for ‘eugenic’ thinking and racism in policy briefings; local councillors penned briefings reflecting on the implicit racial bias of grant awards. This could happen between institutions as well as within them: complaints about pain relief on hospital wards made their way into the minutes of Standing Medical Advisory Committees; and patients confronted haematologists and ward nurses over poor standards of care.

Experience and narrative in histories of medicine

Bivins, Wailoo and Tapper’s historical accounts of SCD, in their focus on high political and medical sources, leave untouched the experience of living with SCD. This dissertation seeks to address this lacuna through a number of published and unpublished patient, family members and activists’ accounts of their experiences
‘living with’ the illness in the broadest sense. These accounts take various forms: patient surveys, autobiography, artwork, and oral history interviews undertaken by the author for this study.

Placing these stories and narratives in dialogue with high histories of Whitehall policy, genetic research and medical practice allows us to do several things. Firstly, it allows us to see that the process of reconfiguring British citizenship took place not only within the spaces of the Welfare State through conflict and contestation, but also as individuals formed their own distinct identities as citizens. Secondly, it reveals the intersections between race, disability, gender and class in ways not accessed by state archives, and reveals the operation of structural racism on a quotidian level. Thirdly, it illustrates that despite the structural racism shaping the services of the NHS, hospitals and community care could be sites of postcolonial conviviality as well as conflict, in which black healthcare workers and their white colleagues forged alliances, and in which SCD patients formed close emotional bonds with those who treated them. Finally, it allows us to explore how experiences of SCD in post-war Britain were variously shaped and influenced by migration, diaspora and family, and it illustrates the continuing influence of African and Caribbean cultures of health and illness on British shores.

‘Illness narratives’ from British people living with SCD began to emerge in the late 1970s and early 1980s, coinciding with an upsurge in the broader publication of ‘illness narratives’ in Britain and the United States, and with the development of the field of medical humanities.\textsuperscript{70} In the 1980s and 1990s the ‘narrative turn’ of the social sciences saw the publication of Arthur Kleinman’s \textit{The Illness Narratives} and Arthur W. Frank’s \textit{The Wounded Storyteller}, works which placed the stories told by sufferers of illness at the centre of their analysis. Kleinman argued that it is through illness narratives that the patient turns a bewildering natural occurrence into a cultural experience. Frank argued that the stories told by sufferers are embodied narratives which can reveal the ‘imaginative effort’ required to understand illness as a lived experience. In the British context, as this dissertation will argue, SCD was a site of postcolonial encounter, as racialized migrants from former colonies (and their

descendants) invoked their citizenship in the hospitals and doctors’ surgeries of the former imperial metropole. SCD illness narratives can therefore be a rich source for understanding an embodied invocation of citizenship and entitlement to care, and for interrogating the ‘cultural experience’ of living with SCD in Britain and simply of being a black person in British medical spaces in the post-war period. In addition to the specific context of SCD in Britain, is what Frank frames as the inherently postcolonial nature of the illness narrative in modern medicine. The sick demand ‘that medicine recognize its need for them’, and in ‘refusing to be reduced to “clinical material” in the construction of the medical text, they are claiming voices’. According to Frank, illness narratives are a genre of postcolonial writing ‘in which the sick emancipate themselves from social and medical imperialism’. Thus the encounters between those living with SCD, their treating physicians, and the state are doubly postcolonial, as non-white people with a lifelong illness.

Much of Kleinman and Frank’s works consider illness to be a rupture in an individual’s life which leads to, in Ronald Dworkin’s words, a ‘narrative wreck’, the sense of being ‘shipwrecked by the storm of disease’. Frank writes that ‘[d]isease happens in a life that already has a story, and this story goes on, changed by illness but also affecting how the illness story is formed’. The nature of SCD as an inherited condition which can be symptomatic from the very first year of life means that, for many of those I interviewed who lived with SCD, the experience of illness with the condition was one of their first memories, if not the first. For many sufferers of SCD, therefore, their ‘illness narrative’ is closely tied to their ‘life story’.

Like illness narratives, there was a surge in life story writing in the second half of the twentieth century, perhaps encouraged by the teaching of self-expression in schools, the workers’ education movement, community theatres and consciousness-raising groups in women’s liberation. As Rebecca Jennings observes, cultural historians have dismissed the retrieval of ‘accurate accounts of individual experiences in the past’ as impossible, and have moved to the forms rather than the

facts of these accounts for their analysis.\textsuperscript{75} Life story writing and telling are understood now to be central to the construction of the ‘narrative self’. While insights from Frank, Kleinman and others on the connection between illness narrative, self and experience are useful, as Lynn Abrams has observed, the historian must ‘think in a distinctive way’ about narrative and oral history, ‘treat[ing] all personal testimony as contingent and the outcome of a process’.\textsuperscript{76} Historians have noted the limitations of the methodology in recovering facts and enabling historical reconstruction, and celebrate, in the words of oral historian Luisa Passerini, that ‘the raw material of oral history consists not just of factual statements, but is preeminently an expression and representation of culture, and therefore includes not only literal narration but also the dimensions of memory, ideology and subconscious desires’.\textsuperscript{77} Oral history projects listening to the voices of migrant communities in Britain and elsewhere have used their testimonies for both these purposes.

Some record the facts of episodes of discrimination that had escaped archival records, as with Brett Bebber’s work with male Sikh interviewees who recalled bullying targeted at their turbans at school and employment discrimination, and the implications of ‘bussing’ practices for Asian children’s education in Southall.\textsuperscript{78} Such usage allows the historian to access perspectives outside archives centred on state institutions. Oral history methods also provide the opportunity to look beyond the archives of formalized migrant community groups, which can bias the picture towards a ‘re-enactment of community myth’. Oral testimony may allow for an exploration of ‘stark internal distinctions and complex interconnections’ to the broader local context – for example, the influence of individual transnational family

structures. Oral history has also been used as a tool for ‘exploring how the ‘subjectivity – knowledge, feelings, fantasies, hopes and dreams – of individuals, families and communities informs and shapes the migration experience at every stage and is in turn transformed by that experience’. Emma Robertson’s oral history of Julie, a Ugandan Asian woman who moved to York in 1972, considers how Julie’s narrative reflects key aspects of her subjectivity and her sense of belonging, difference and home. Both approaches elicit valuable historical work: Alistair Thomson argues that ‘sophisticated theoretical awareness about memory and subjectivity which characterizes recent work should not displace or discredit the earlier, more empirical and political claims for the oral histories of migration’.

I use both approaches in this dissertation. I utilise oral testimonies to fill in the gaps left in documentary sources about the function of state negligence of SCA, such as testimonies from healthcare professionals on meetings with Local Health Authorities or senior members of staff to lobby for services. These perspectives survive only in glimpses in the documentary testimony because medical personnel would have risked their careers in revealing these internal struggles. One doctor recalled an incident in which she was interviewed for a film for the Sickle Cell Society, and told the camera that her boss at the hospital did not care about black people. ‘[M]y face was on camera,’ she recalled, and ‘in the end I said, can you delete that bit… it will be detrimental to the progression of my career in the future. So I asked them to delete that bit -- but that's how I felt. That they don't care, because it's a black people's thing’. Policy documents and publications by these healthcare workers usually only hint, if at all, at the anger of many healthcare professionals and the extent to which they saw inaction as a symptom of individual and institutional racism. Oral history collection can provide retrospective access to these self-censored views and to personal relationships and discussions that elude a purely

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83 Catherine (pseudonym), interview with GR, 9 December 2018.
archival view. This dissertation also interprets the illness narratives and life stories of patients and their families both as revealing the individual impact of structural racism and the ways in which they articulated their entitlements to care, but also to draw out the subjectivities of individuals, families and communities and their shaping of the experience of migration, health and illness in post-war Britain.

The oral history project began with the assistance of the Sickle Cell Society, who published a call for participants on their website and social media pages in the autumn of 2017, seeking individuals aged 18 and over with experience of SCD as a patient, family member or healthcare professional. I interviewed 21 people, consisting of six healthcare professionals, three family members, and eleven people living with SCD, sickle cell thalassaemia, or sickle cell haemoglobin C disease. These interviews usually took place in the individual’s home or at the campus of University College London, and were one-off interviews lasting between 90 minutes and two hours. Due to the date ranges of this thesis I have substantively used the testimony of six of the interviewees, including patients, family members and healthcare professionals. Though this is undoubtedly a small sample, as Francesca Battisti and Alessandro Portelli argued, there are advantages to focusing on the ‘meanings and implications of a few significant narratives’ rather than generalising from a broader sample.\(^{84}\) I do not claim that the narratives and experiences of the interviewees I cite are representative, but that the ways in which these narratives and experiences diverge and coalesce can tell us about the myriad ways in which individuals with SCD and their families can understand and make meaning from medicine, migration and the NHS.

All of those with the condition who I interviewed were Black British, Black Caribbean or Black African, and so I must address the ways in which my position as a white British woman shaped the interviews.\(^ {85}\) As a white person, there is no amount of research or reading that I could do that would enable me to truly


\(^{85}\) Whether it is ever appropriate for white researchers to conduct oral history research into black experience in Britain has been contested – Joanna Bornat, Judith Burdell, Bridget Goom and Paul Thompson, ‘Oral History and Black History: Conference Report’, *Oral History* 8:1 (Spring 1980): 21-23.
understand what it is to experience racism. What Peggy McIntosh has called the ‘matrix of white privilege’ has shaped my experience and view of the world, and whiteness has ‘protected me from many kinds of hostility, distress, and violence’. 86 This undoubtedly affects all my research, archival as well as interview-based, but it was in the course of conducting these oral histories that the role of this gap in my experience became palpable. I believe this had an effect in two primary ways: what my interviewees felt comfortable saying to me, and what I felt comfortable asking them. Regarding the first effect, I found that though topics of race and racism are key to my research questions and play a significant role in the history of SCA in Britain, interviewees did not raise it as often as I had expected, although many still did. It is hard to gauge the extent to which this was because some felt this did not apply to their experience, or because of uncertainty on the part of interviewees about how receptive or understanding I would be to such an angle. It is possible or even likely that some interviewees, consciously or subconsciously, decided against sharing these experiences or thoughts during our interview.

In terms of what I felt comfortable asking interviewees, during the interviews I felt uncomfortable when I came to several questions I had included in my draft questionnaire, and in the moment often decided against asking them. An interview is a social encounter, and (of course) not insulated from wider political contexts by its academic purpose. Some questions that I had drafted ultimately felt inappropriate in an interview context. I was wary of the possibility of implicitly reinterpreting the interviewee’s experience through my line of questioning. One question on my questionnaire, which asked about the extent to which the interviewee identified as ‘British’ or any other nationality, was never asked. Given that many of my interviewees had been born in Britain, I feared that such a question – though initially conceptualized to open up the topic of identity – would be a microaggression when coming from a white British interviewer. 87 As Simon Dyson found when undertaking a community survey in 1995, such questions also risk not only enacting

microaggressions but may be construed as threatening. When Dyson inquired about an interviewee’s area of geographic descent, the interviewee reacted with distress, feeling themselves to be ‘subjected to a nationality test’. As several of my interviewees were not domiciled in Britain, this risk is arguably even more of a concern in the present context of the ongoing Windrush scandal and the hostile environment. Cynthia Brown reflected in 2006:

For how much longer are we going to ask people who have lived in Britain for thirty, forty or fifty years where they came from and why – the very same questions, as an organization for refugees and asylum seekers in Leicester pointed out to us, that are asked of them by immigration officials? Does a continuing focus on festivals and celebrations simply produce more of what Sav Kyriacou described in this journal in 1993 as ‘nice, safe material that would allow the host community to understand our religious customs, food and traditions and be more tolerant towards us, and not to talk about our suppression and exploitation at the hands of racists’? But powerful as oral histories of racism undoubtedly are in promoting tolerance and understanding, too narrow a focus on these issues may also reinforce the ‘victim’ status that many of us on the receiving end of racism have long since discarded.

As Julian Simpson has recently argued, ‘asking different questions, about how migrants and imperial links have contributed to the making of European nations’, must be the way forward for oral historians of post-war British migration.

Chapter outline

The chapters that follow approach this subject by looking at actions taken and discourse on sickle cell in five ‘spheres’, in which sickle cell took on different

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88 Dyson, “Race”, ethnicity and haemoglobin disorders’, 127.
meanings. Ordered from ‘top’ to ‘bottom’, they present a cross-section of discourse, action and emotion on ‘race relations’, institutional racism, migration and the body, focused on the single issue of SCA, across a fifty-year period.

Chapter 1 addresses SCA in medical research, and traces through it a transition from racial anthropology and race science to population genetics. At the same time as scientists were enlisted by the UNESCO statements on race in the 1950s and 1960s to deconstruct notions of race as grounded in biology, a series of scientific discoveries positioned SCA as a subject of intense scientific interest and resource. This chapter focuses on a Medical Research Council-funded unit of biochemical researchers in Cambridge, led by German emigré scientist Hermann Lehmann, a Jewish refugee from Nazi genocide. His initial research interests articulated haemoglobin variants such as SCA as an opportunity to investigate and diagnose ‘race’ at a genetic level, and hypothesise about pre-historic ‘tribal’ movements in central and southern Africa and India. However, as haemoglobin types proliferated across the researched populations, Lehmann and his colleagues implicitly deconstructed notions of concrete racial difference by identifying genetic traits as mutable and present in all populations in different frequencies. At the same time, their research methods relied on contrasting an individual’s racial nationality and physical appearance against the evidence of blood tests, in practice reifying typological divisions of human difference and leaving the door open for the more recent returns to scientific notions of racial difference. The MRC Abnormal Haemoglobin Unit sat within both a domestic network of clinicians, who collected blood samples from the migrants in their care, and an international network of clinicians, made up of dwindling numbers of colonial medical officers as well as field researchers in India, South Africa, the Mediterranean and the Middle East. This chapter argues, however, that despite many samples coming from British hospitals, Britain was not seen by the MRC as an appropriate location for SCA research. Although Bivins has argued that SCA was reframed from a tropical medicine to one that came home, this chapter argues that the MRC and scientists continued to locate SCA, and its research, overseas. Ultimately this emphasis on overseas research, and the absence of discussion of the trait in British citizens and residents, constructed haemoglobin disorders as minority concerns for the British state.
Chapter 2 examines the paralysis of the British government when it came to taking action on SCA. On the face of it, this period was characterised by short flurries of interest and activity punctuated by long gaps of delay and disinterest. An examination of files from the Department of Health and Social Services and the Department of Environment reveals that this stagnation was produced by two concerns – anxiety around the appearance of racism or eugenic thinking that government action on a ‘racial’ genetic disease might suggest, and an enduring belief that a health issue affecting a minority of the British population should not receive ‘special treatment’. Between 1962 and 1995, policymakers in Whitehall shifted from perceiving sickle cell as a politically problematic issue to understanding it as a touchstone to signal the government’s commitment to addressing ‘racial disadvantage’ in the wake of unrest and rioting in the early 1980s. Funding for SCA became available at a local level following the riots of 1981, and SCA clinics became a common feature of programmes tackling ‘racial disadvantage’ in the wake of Lord Scarman’s report on the Brixton uprising. DHSS surveys and mapping projects between 1969 and 1975 had reframed the disease from racial to geographical – an ‘urban’ disease of the ‘inner cities’, terms which by the 1980s had become by-words for racial violence and race riots. Therefore, instead of funding SCA services through NHS main programmes, DHSS outsourced the work of screening and education to the Urban Programme within the Department of Environment. Some of this funding led to the development of a localised and patchy provision for sickle cell pioneered by nurses, health visitors and haematology departments.

Chapter 3 considers SCA within the National Health Service. This chapter argues that a sense of SCA as a ‘tropical’ or ‘foreign’ illness meant that Local Health Authorities and senior hospital management continually underestimated the prevalence of SCA even in areas with larger African and Caribbean populations, and were reluctant to fund sickle cell centres and screening programmes as a result. Individual doctors and nurses, with little medical training about SCD, frequently perceived patients enduring sickle cell crises to be drug addicts, or saw affected children as victims of child abuse. This chapter explores the early years of the Brent Sickle Cell and Thalassaemia Centre, founded in 1979 and the first specialized sickle cell centre in Europe – and other centres in Lambeth, Liverpool and
Manchester. These centres generated the clinical consensus for a National Screening Programme and guidelines for treatment attempted to counter widespread racist conceptions of adult SCD patients as drug addicts and of black families as fractured. While action on SCA was stalled at the level of DHSS and the MRC, haematologists, nurses, health visitors and paediatricians generated clinical consensus and political energy on a local level.

Chapter 4 addresses advocacy groups such as OWAAD, OSCAR and the Sickle Cell Society between 1975 and 1995. Using SCS archives, activist memoirs and oral histories, this chapter will explore how these organisations and individuals lobbied government, raised funds and articulated the condition as a symbol of the institutional racism of the welfare state. These groups formed lines of communication between African and Caribbean communities and NHS clinicians, communicating sensitive information about genetic health to black families, articulating the need for symptomatic research and challenging medical fascination with the genetic trait itself. Situated between black feminist collectives, African and Caribbean church groups, and the NHS itself, sickle cell activist organisations were agile bodies who framed the condition as a symbol of the ‘uncaring arm’ of the British welfare state. They provided psychological and social support for patients and families, and from the discourse of SCS and OSCAR developed a collective language of self-management and identity that could be adopted and used by people living with the condition.

Finally, for those who lived with it, sickle cell was a painful, life-threatening condition often deeply misunderstood by health professionals. Chapter 5 accesses the experiences of those with SCD and their families, using a combination of archival research and oral history research. First it explores the life and work of the artist Donald Rodney, who lived with SCD until his death in 1998. For Rodney, the hospital could be a site of creativity and meaning-making, and he used his own body and his illness in work commenting on British national identity, Black masculinity and the state. The chapter will then turn to oral testimonies to explore the experience of migration in illness narratives of SCD. Written sources documenting the experiences of those with SCD in Britain were only published in the 1980s and afterwards, but the use of oral histories allows us to reconstruct experiences back to those of Windrush
migrants at the beginning of the 1960s. For first generation migrants with SCD, the process of migration and diagnosis meant that the NHS reframed their understandings of their bodies, and reordered their memories of their families. Finally, this chapter will argue that people living with SCD claimed their citizenship not just through political organisation, but also through their experiences of health and illness, as they invoked their right to care, formed relationships with the professionals who treated them, and reflected on their relationship to the welfare state.
Chapter 1: The ‘great British haemoglobin king’: Race, migration and postcolonial genetic research in the clinic and the field, 1953-1985

Between 1949 and 1985, a small and fluctuating community of biochemists and doctors were employed in investigating and cataloguing variants in human haemoglobin. Their research was first stimulated by the ‘mystery’ surrounding sickle cell anaemia American physicians had noticed the trait in African American patients, and colonial medical officers had encountered it in people in Uganda and Ghana. In the late 1940s and early 1950s, researchers in sub-Saharan Africa sought to answer why the trait was so prevalent in the region, when the effects of the disease (when a person inherits a copy of the trait from each parent) were so devastating that adult cases were ‘extremely rare’. This question was settled in 1954, when Alexander Allison demonstrated that carriers of the SCA trait were resistant to malaria falciparum through a series of ‘field’ tests in which he infected 30 Ugandan male ‘volunteers’ with the disease and observed its progress. J.B.S. Haldane hypothesised in 1949 that the trait conferred a selective advantage, an example of Darwinian evolution in action. In 1957, in the laboratory of Max Perutz in Cambridge, Vernon Ingram showed that SCA haemoglobin differed from normal haemoglobin only by one of its components. A change in the sequence of the DNA could be identified as the cause for this specific amino acid substitution in haemoglobin. SCA was the first genetic condition in which the cause was identified at the molecular level, and the paradigmatic case for the claim that a single change in the DNA sequence, a ‘mutation’, could have dramatic effects on the human body.

3 Harper, A Short History of Medical Genetics, 131.
haemoglobin variants became ‘a powerful tool for genetic analysis on a molecular level and more generally for molecular structure-function relationships’.  

But SCA had another function for biochemists and scientists – since its first discovery (in Western medicine) in 1910 in the United States, it had been seen as proof of ‘blackness’ that lay below the skin, in blood itself.  

By the late 1940s, the research community that had coalesced around SCA used the condition to investigate not just SCA’s epidemiology, the structure of haemoglobin molecules, and clinical genetics, but also to ask what the present day distribution of the trait meant for human relatedness. In 1949, a 36-year-old Colonial Medical Research Fellow named Hermann Lehmann conducted surveys of ‘the sickling phenomenon’ in Uganda and Tangyanika, and found much more variation between language groups than previously observed. He used this variation to speculate about the ‘origin of East Africans’, which he published in 1954 in the Eugenics Review.  

Lehmann – a German Jewish refugee – devoted the rest of his career to the path opened up by SCA. Over the next three decades, he used haemoglobin variants to ask questions about both the structure and function of the haemoglobin molecule, and the history of human migration and relatedness. Lehmann established a research network that collected, identified and analysed over 100 haemoglobin variants. Referred to as ‘the doyen of haemoglobin variants’ or ‘the great British haemoglobin king’ by his contemporaries, his Abnormal Haemoglobins Unit at Cambridge was funded by the Medical Research Council from its foundation in 1963, and designated a haemoglobin reference centre by the World Health Organisation in 1965.  

But by the early 1970s his research was increasingly irrelevant to the interests of the MRC, whose SCA research portfolio began to focus on clinical treatment, screening programmes and the ‘natural history’ of the disease. The arc of Lehmann’s career illustrates the meaning of SCA in this period, and how the shadow

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5 Tapper, In the Blood, 13.  
of eugenics, enduring questions about race, and decolonization and migration shaped scientific research and understanding of the condition in Britain and overseas.

SCA research serves as a case study in the ‘handover’ between racial anthropology to population genetics in the post-war medical research community centred in Britain. As many historians of science have shown, this was a linguistic and social transition, rather than a truly methodological or conceptual shift.\(^8\) Practices and aims associated with the eugenics movement, such as selective breeding, the use of racial typologies and physical measurement, continued in medical research during this period.\(^9\) However the notion of ‘populations’ was in the ascendant over the more eugenicist ‘typologies’ or racial ‘types’. Scientists increasingly leaned towards the view that physical traits ‘were coded by genes that could be found in every identifiable population, albeit at greater or lesser frequencies’\(^,10\) This population thinking reinterpreted the notion of evolution ‘based upon the struggle between various ‘types’, with one based upon polymorphic populations made up of unique individuals’ – emphasizing variety both within, as well as between, different population groups. By the 1970s, use of the term ‘eugenics’ had become a ‘useful strategy of demarcation’, a word by which scientists could distance their work from accusations of discrimination.\(^11\) While medical researchers erected a boundary between eugenics and population genetics – cauterizing the reputational damage to science following the horrors of the Holocaust – many of these medical researchers had lingering professional and personal relationships that they were loath to reject. This chapter argues that during the 1940s and 1950s,


\(^10\) Bivins, *Contagious Communities*, 307.

many of these relationships were reformulated from those between ‘colonial researchers’ and their sometimes nameless blood donors, to that of ‘international development’ and transnational friendship between eminent Western scientists and ‘local’ blood workers. These research networks and laboratories began to shift away from the straightforward extraction of resources and generation of ‘knowledge’ that characterized colonialism, towards a postcolonial conviviality and collegiality. Paul Gilroy has described this conviviality as ‘the processes of cohabitation and interaction that have made multiculture an ordinary feature of social life’ in Britain during and after decolonization.\textsuperscript{12} Lehmann was a convivial, cosmopolitan lynchpin in a global network increasingly held together by expertise, resources and favours rather than colonial power.\textsuperscript{13}

Roberta Bivins has argued that scientific understanding of the haemoglobinopathies as tropical and racial meant that organized clinical research on the conditions was located in colonial and post-colonial ‘field’ institutions. Meanwhile high-status ‘basic’ research was funded in Britain.\textsuperscript{14} She argues that this changed when a generation of colonial medical researchers returned to Britain, where they ‘took up roles as advocates for better funded (elite, biomedical) research into once-tropical diseases’.\textsuperscript{15} This chapter will argue that the ‘field’ could not be transplanted so easily. In London and then Cambridge, Lehmann valued access to subjects overseas, particularly in Africa, the Middle East, South Asia and South America – both through funded field research and by cultivating relationships with local workers. An examination of the casebooks in which samples sent to the MRCAHU were logged, and publications and research practices, reveals that Lehmann and his colleagues struggled to reconcile their research with the increasing numbers of British residents affected by sickle cell or other haemoglobin variants as a result of

\textsuperscript{12} Paul Gilroy, \textit{After Empire: Melancholia or convivial culture?} (London and New York: Routledge, 2004): 136.
\textsuperscript{14} Bivins, \textit{Contagious Communities}, 325.
migration from former colonies. When the MRC’s research agenda moved on from Lehmann’s population genetics to the question of symptomatic sickle cell treatment in the mid-1970s, the Council chose to fund a unit in Jamaica led by a British clinician. This chapter will argue that there was a limit to how much tropical medicine ‘came home’ in this period. Lehmann’s research strived to strip away the migration histories of their subjects, and return them (abstractly) to an original ancestral home which could render their blood genetically legible. Migration to Britain from the former Commonwealth, as well as colonial histories of migration and intermarriage, frustrated these efforts.

Connected to the shifting fortunes of eugenics in the scientific community was a question mark over the relevance of ‘race’ in medical research. In a series of statements in the 1950s, a series of United Nations Educational, Scientific and Cultural Organisation (UNESCO) statements deemed ‘race’ to be an inappropriate category when discussing national or linguistic groups, and defended it as ‘the exclusive preserve of expert biologists’. According to UNESCO, scientific research about human difference and relatedness could be ‘a remedy for prejudice’. This chapter shows that this project of remedying prejudice through population-based genetics involved reconstructing past patterns of migration, to illustrate the mixed picture of human heredity, and mapping the blood characteristics of present-day groups and their ancestors. However, in building this new picture of human history as the product of constant migration, these researchers struggled with the implications of present-day migration for their results. The methodologies and conclusions of the MRCAHU reflected researchers’ anxieties about migration, intermarriage and racial ‘purity’ contaminating their data. As Melbourne Tapper argues, researchers continued to use sickle cell anaemia as a marker of race – but

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their research concerns and conclusions reflected the preoccupations of a postcolonial British identity crisis.\textsuperscript{18}

The first section will examine Edward Ramsden’s assertion that eugenics became subject to ‘boundary-work’ by demographers and geneticists during the 1950s and 1960s, who denounced it in efforts to establish their fields as ethically and scientifically credible.\textsuperscript{19} This section will use Lehmann’s research into SCA and his navigation of personal relationships to explore this boundary-work, asking where this boundary lay in the science and anthropology of human difference, and how the scientific credibility of population genetics was established. The second section will explore how Lehmann and his colleagues made sense of the blood samples sent to their Cambridge laboratory, and sought to impose a comprehensive history of human relatedness onto a research pool complicated by long histories of migration and intermarriage. The third section will consider the global network that facilitated this research, the shifting boundaries between the clinic, the field and the laboratory, and the incorporation of local workers into a framework of scientific ‘international development’ that continued to benefit British scientists such as Lehmann.

**Credibility, friendship and boundaries between eugenics and population genetics, 1951-62**

In 1953, Lehmann — then living in London and working as Professor of Pathology at St Bartholomew’s Hospital — wrote to the biologist Dorothy Needham (1886-1987), thanking her for a weekend’s hospitality from her and her husband, the biochemist, historian and sinologist Joseph Needham (1900-1995). It seems that the visit was not simply a social call, but an opportunity to workshop Lehmann’s academic career. His work in the Royal Army Medical Corps (RAMC) in India, investigating hypochronic anaemia in troops, had been followed by a Colonial Medical Research Fellowship in Malnutrition and Anaemia in Uganda for three years. There he had first encountered SCA, coinciding with Linus Pauling and Harvey Itano’s use of moving boundary electrophoresis to determine a difference between sickle cell and normal

\textsuperscript{18} Tapper, *In the Blood*, 58.
\textsuperscript{19} Ramsden, ‘Confronting the Stigma of Eugenics’, 853-84.
haemoglobin. ‘It was an exciting time to work in tropical Africa,’ Dacie wrote, ‘and Lehmann made the most of his opportunities.’ He had collected blood from people in Uganda and India, and published a series of papers demonstrating that – contrary to scientific consensus – SCA was found in places and people other than Africa and Africans.

Now, Lehmann was looking to his future. ‘With the partially deflating but oh so cleansing and also comforting experience of having one’s publications surveyed — it was a wonderful evening,’ Lehmann wrote. ‘Whatever happens to the special ScD [sickle cell disease] problem, it has clarified my mind to have this round table conference, and I am grateful that there is someone of both your eminence who agrees to wade carefully and sympathetically with me through the shambles of my past.’ The Needhams had been informal mentors to Lehmann for nearly two decades. Joseph Needham, along with the Society for the Protection of Science and Learning (SPSL, now known as the Council for At-Risk Academics), secured Lehmann’s move from Nazi Germany to Cambridge in 1936. The couple took the penniless young refugee with limited English under their wing, giving him use of their house when they were away, and introducing him to other eminent thinkers such as C.P. Snow. With the outbreak of war in 1939 he was interned as an alien in a Liverpool camp, but his ‘friends in high places’ had secured him a comparatively quick release.

The Needhams’ opinions on SCA do not appear in Lehmann’s letter or elsewhere, but Needham was himself invested in a post-war project to expunge racist thinking from science. He, alongside the geneticists Theodosius Dobzhansky

22 Letter, H. Lehmann to D. Needham, Archives of Girton College, Cambridge, Papers and Correspondence of Dorothy Needham, A40, 1/4/11/15. The letter is not dated, but as Lehmann refers to having examined a proof of the first volume of Science and Civilisation in China during this visit, which was published in 1954, I have dated it to late 1953.
23 Letter, A.J. Makower to J. Needham, 26 March 1936, M.49 Correspondence, Papers of Joseph Needham, University of Cambridge Archives.
25 Hermann Lehmann, oral history interview with Lyn E. Smith (26 January 1980), 55 minutes, 4589 Sound Collection, Collections of the Imperial War Museum.
and Curt Stern, had assisted in the drafting of the first UNESCO statement on ‘race’ three years earlier. This statement sought to address one of UNESCO’s central concerns – its constitution in 1945 had declared that

The great and terrible war which now has ended was made possible by the denial of the democratic principles of the dignity, equality and mutual respect of men, and by the propagation, in their place, through ignorance and prejudice, of the doctrine of the inequality of men and races.

The first statement had not challenged what it described as ‘the biological fact of race’, but had two primary aims: to decouple the relationship between ‘race’ and ‘national, religious, geographic, linguistic or cultural groups’; and to clarify that there were no ‘mental’ or ‘social’ differences between ‘races’. Where race and national or religious groupings had been linked in the past, the authors argued, it had ‘taken a heavy toll on human lives and caused untold suffering’. The solution for the layperson would be to ‘drop the term ‘race’ altogether and speak of ethnic groups’, the collective argued – and leave the question of race to anthropologists and scientists. The statement listed the racial categories ‘Caucasoid’, ‘Mongoloid’ and ‘Negroid’ as neutral scientific terms. These words, already considered anachronistic in other quarters, were deployed here almost as bulwarks against scientific racism. The statement suggested that what made a scientific text racist was whether a claim of biological difference between ‘races’ was accompanied by a claim that this difference made one superior or inferior to the other. That Lehmann was encouraged in his research into SCA by one of the statement’s authors is indicative of the project’s relevance to contemporary scientific and moral agendas.

In Uganda Lehmann surveyed schoolchildren, policemen and prisoners, and recorded a higher rate of sickling than reported in previous literature. His subsequent research then focused on tribal groups, and in 1949 he and A.B. Raper published a

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paper contrasting tribal sickling rates in the journal *Nature*, which showed that the sickle cell trait in Uganda varied between less than one per cent and 45 per cent across linguistic groups. They suggested that the variation between low and high sickling rates was due to the extent of ‘contact’ with ‘Hamitic invaders’ – that where low sickling occurred, there had been intermarriage with Hamitic peoples, and that high rates of sickling occurred in ‘remote’ or ‘secluded’ tribes. In this, Tapper argues, Lehmann and Raper were offering a ‘scientific’ basis for the ideas of C G Seligman. In his 1930 work *The Races of Africa*, Seligman had argued that variation in the physical appearance and ‘sophistication’ of Nile Valley populations could be explained by the extent of intermarriage between the ‘pastoral Caucasian’ Hamites, who he deemed superior, and the ‘dark agricultural Negroes’. Lehmann packaged this theory even more explicitly in his *Eugenics Review* publication on the subject in 1954. In a piece incorporating analysis of ‘pastoral’ habits, musical instruments, language and physical ‘features’ (with several printed photographs of Ugandan men), Lehmann evaluated the evidence for two theories. The first was Allison’s hypothesis that SCA was linked to the geographical incidence of malaria, on which Lehmann observed that ‘[t]his attractive theory will have to be carefully examined, but the fact remains that the higher the sickling rate the lower will be the admixture of physical Hamitic features in any one Bantu tribe’. The second was a theory by the biologist and anthropologist A.C. Haddon, which Lehmann said he ‘often discussed – though never published’, strongly suggesting that Lehmann had heard it from him in person while at Cambridge. Haddon had advanced that at ‘some time in the Neolithic period a profound change took place in the skeletal type of the East African. Whereas previously the configuration was elegant and small, there appeared all at once coarser and bigger structures’, so suddenly that Haddon believed only migration (or ‘invasion’ as Lehmann put it in this paper) could account for it.

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32 Tapper, *In the Blood*, 79.
Significantly, though Tapper correctly identifies C.G. Seligman as the most famous expounder of this diffusion thesis, Lehmann explicitly referenced Haddon instead. Haddon and Seligman both believed the ‘white race to have progressed beyond the black race’, but Haddon also had a reputation as a fighter ‘on behalf of the [racially] oppressed’ among his contemporaries, had attended the First Universal Races Congress in 1911, and was a critic of concrete racial taxonomies. Lehmann’s respectful citation of Haddon, his use of ‘pastoral’ habits as well as serology in his analysis, and his scepticism about a Darwinian explanation, all suggest that while his sympathies lay with an older traditional school of British physical anthropology, he preferred to ally himself with Haddon’s (comparatively) ‘progressive’ expression and reputation. Haddon had published in 1937, along with J.S. Huxley and A.M. Carr-Saunders, the work *We Europeans: A Survey of “Racial” Problems*, contending that scientific study of ‘race’ was deeply flawed and rejecting the use of ‘race’ to justify discrimination. Lehmann’s focus on these anthropological theories from a prior generation of anthropologists also indicates his devotion to ‘the field’ in research. Both Haddon and Seligman were part of the group that journeyed to the Torres Straits in 1898, which Barkan describes as ‘the first British anthropological expedition’, marking the discipline’s move ‘from the armchair into the field’. In fact, Lehmann explained that it was Haddon’s theory which led him to seek out SCA in India – a trip which became the source of his major scientific contribution, and the foundation of his future career.

On these research trip to the Andaman Islands and the Nilgiri Hills in India in 1953 and 1954, Lehmann and the blood transfusionist Marie Cutbush found the sickle cell trait in the first sample they took – from an Indian laboratory technician, a sample they had taken simply to test their technique. From this research they published the paper ‘The Sickle-Cell Trait: Not an Essentially Negroid Feature’,

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37 He also thanked A.E. Mourant, and the physical anthropologist and ‘race mixture’ expert J.C. Trevor, ‘for supporting what must have then seemed a wild scheme of visiting India in search of the sickle cell trait’. Lehmann, ‘Distribution of the Sickle Cell Gene’, 105-7; Marie Lawrence, ‘Obituary: Dr J.C. Trevor’, *Nature* 216 (November 4, 1967): 523.
disproving the previous consensus that the trait was ‘essentially African’. As the title of this paper indicates, this work was the first to break the relationship between the SC trait and skin colour, collapsing the essentialised view of the SC trait – but not, by any means, of ‘racial’ types themselves. Lehmann’s alternative explanation for the incidence of SCA in southern India and the Andaman Islands was that SCA had migrated, via so-called ‘Vedddian’ tribal movement from South Asia to the Middle East and finally West Africa. In this he again sought to explain the social groupings of East Africa according to degrees of intermarriage with groups from South Asia. Though Lehmann and Cutbush argued that the SC trait could not be used as a ‘tracer of African ancestry’, they ‘did not question the existence of racial features and continued to see sickling as a marker of racial affinity’ and indeed believed there were other traits that could be used as a direct ‘tracer’. Their hypothesis was disproved by Anthony Allison’s 1954 paper, which proved J.B.S. Haldane’s hypothesis that carriers of the sickle cell trait were resistant to malaria. Despite Lehmann’s false hypothesis, his study with Cutbush defined the research agenda that would shape his career – chronicling and mapping the variants in human haemoglobins across global populations.

Lehmann’s demonstration that SCA and other abnormal haemoglobins could be found across the world, in greater or lesser frequencies, was a critical moment in the mid-century movement within genetics towards a population-based paradigm. Yet, his conclusions show that his research agenda was set by the literature of early twentieth-century scientific racism. His research was seized upon by the Eugenics Society of Britain, Bivins has argued, because it reconfigured topics that had always been of interest for them within the new, cutting-edge, eminently evidence-based field of ‘molecular genetics’. He addressed a 1953 symposium of the Eugenics Society on the topic of SCA and race. But despite the continuities between pre-war eugenics and Lehmann’s early work, his credibility was never in doubt. He

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40 Tapper, In the Blood, 84-5.
41 Ibid, 84. Cutbush and Lehmann also argued that the Rho blood subtype could be used as a tracer of African ancestry.
43 Bivins, Contagious Communities, 306. The Eugenics Review was shuttered in 1961 and replaced by the more acceptable Journal of Biosocial Science.
maintained links with – and cited in his publications – expounders of scientific racism. Lehmann’s involvement in a 1962 legal dispute between the Royal Anthropological Institute (henceforth RAI) and the journal *Mankind Quarterly*, particularly illuminates this ambivalence.

*Mankind Quarterly* had begun circulation in June 1960, describing itself as ‘dealing with race and inheritance in the fields of ethnology, ethno- and human genetics, ethno-psychology, racial history, demography and anthropo-geography’, and openly supported both South African apartheid and American segregation. *Mankind Quarterly* had close links to the International Association for the Advancement of Eugenics and Ethnology, and around these two institutions coalesced an international network explicitly positioned against the US Civil Rights movement. It was edited by two men: the Canadian botanist Reginald Ruggles Gates, who was deeply embedded in the British eugenics movement of the 1920s and 1930s and briefly married to the birth control advocate Marie Stopes. The second was Robert Gayre, a Scottish eugenicist who ‘inhabited the margins of academia’. The RAI, on the other hand, was one of the first British scientific institutions to register the challenge of Nazi race science. Their 1934 ‘Race and Culture’ conference, though ‘it achieved little in the way of consensus about the importance of race in science… indicated a desire to develop a British united front as a challenge to the dogmatic racism of the Third Reich’.

Gayre and Gates sued the RAI for libel when it published a letter that was highly critical of the new *Mankind Quarterly* in 1961. The letter was an open letter of resignation from the board of editors of the *Mankind Quarterly*, written by the Slovenian anthropologist Božo Škerlj in the RAI’s journal *Man* (today the *Journal of the Royal Anthropological Institute*). In the letter Škerlj argued that the content of the journal was:

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46 Ibid, 249.
quite incompatible with my conscience as a scientist and an affront to the bitter memories I have of the anguish suffered during World War II by the peoples of Europe and of my own country in particular – not to mention what I personally saw and experienced while a prisoner in Dachau – as a result of the abuse, for political motives, of the noble and dispassionate aims of anthropology.48

Škerlj distanced himself and the ‘dispassionate’ discipline of anthropology from Mankind Quarterly, and explicitly linked it to the Nazi genocide perpetrated in the name of eugenics and racial purity. Gayre and Gates launched their libel suit over a year later in February 1962 – possibly prompted by a deeply unfavourable review of Mankind Quarterly in the September 1961 issue of Man. This review, written by the biological anthropologist Geoffrey Ainsworth Harrison (who would be elected President of the RAI in 1969), specifically took issue with Gayre’s argument about population genetics. Harrison summarised Gayre’s argument as:

there exist a number of completely discrete races of man and that geneticists and anthropologists are incompetent if they happen to see that the pattern of variation over large geographical areas shows a continuous gradation of change with polar types connected by populations displaying practically every degree of intermediacy.

This framed the central intellectual division between the RAI and Mankind Quarterly as population-based versus typological definitions of race. The review ended with Ainsworth Harrison hoping that Mankind Quarterly ‘will succumb before it can further discredit anthropology and do more damage to mankind’.49 Škerlj sought to defend his reputation, as did the RAI, by publicly dissociating themselves from Mankind Quarterly. The publication in turn fought this dissociation through its libel suit.

That April, Lehmann became an intermediary between the two parties after Gates approached him ‘as a friend’ for advice. During this conversation, Lehmann

48 Škerlj, ‘Correspondence’, 172.
told Gates ‘what a scandal it would be if the action were proceeded with, and begging him to drop it’ and also notified him that Škerlj had died the previous year. The following day, Gates telephoned Lehmann to suggest ‘that some form of statement in Man dissociating the R.A.I. from Škerlj’s letter, or from contributions in general, might make withdrawal possible’. Lehmann then went to see W.B. Fagg, editor of Man, to suggest this solution and in Fagg’s words

I telephoned White [the solicitor] and had Lehmann repeat it to him. I said that in principle there was no reason why any or all of our publications should not carry a disclaimer… He advised Lehmann to suggest to Gates that he get his solicitors to approach ours… Lehmann then, in my presence, telephoned Gates and made this suggestion to him and his wife – who appeared to feel that we should apologize (which Lehmann made clear was impossible). Mrs Gates, though admitting she had not read Škerlj’s letter, appeared somewhat indignant about it, but Lehmann did his best to mollify her and get her to use her influence in favour of withdrawal, in their own interest. 50

Lehmann’s was a curiously impartial voice in this dispute – approached by Gates as a valued advisor (the origin of their connection is not clear), and trusted by Fagg and the RAI’s lawyers as a member of the Institute’s Council to act in its best interests. In bearing these messages back and forth between the two parties, he refrained from refuting or supporting the comments made by either Škerlj or Gates. Though his primary objective was to prevent legal action against the RAI, his friendship with Gates appears to have been marked with genuine sympathy and respect. When Gates died in August 1962, Lehmann wrote to the Secretary of the RAI disclosing that

Ruggles Gates was indeed very distressed over the libel action and he told me that he repeatedly pressed Rubinstein [his solicitor] to come to an agreement… He told Rubinstein that “he was losing his friends” over this. He intended to come with his wife to the Garden Party and was much taken

aback when I strongly advised him against this. In his somewhat confused and senile way he said that he had considered his action as a “friendly action”, and in fact told me that he was engaged to get a considerable sum of money from the R.A.I., but asked me not to mention this to anyone… If the action contributed to his death – which is rubbish – the fault lies with his solicitors.51

In this implicit plea for posthumous forgiveness for a ‘confused and senile’ Gates there is the clear implication that if Gates was losing his friends, Lehmann was not one of them. Others were not as tolerant of Gates’s views – he had been dismissed from Howard University in Washington, DC in 1947 following a student petition accusing him of teaching racist theory, his papers were frequently rejected by academic journals for their racist content, and the RAI had already received much correspondence objecting to Gates’s views, including one letter from Malaya’s Commissioner for Aboriginal Affairs.52

Lehmann did not extend this sympathy to Gayre, reporting in the same letter that in Copenhagen he had met a South African geneticist ‘who told me that Gayre presided over a meeting there on races which gave considerable support to Apartheid and dismayed the rightminded people there’, and promising to send over any relevant newspaper reports that might benefit the case.53 Yet, the views of Gates and Gayre were very similar – in fact, Gayre had been standing in for Gates at the meeting, which had been the second conference of the pro-apartheid South African Genetic Society.54 Gavin Schaffer goes so far as to say that Gates and Gayre were ‘carbon cop[ies]’ of one another, particularly in their hostility to the post-war, UNESCO vision of race and racial difference.55 Lehmann’s equable response to Gates is especially surprising given Gates’s well-known unwavering anti-Semitism,

52 Schaffer, “‘Scientific’ racism again?”, 255; see also RAI Archives, A98/2/6, correspondence Dr. A.T. Carey to W.B. Fagg, 5th April 1962 and A98/2/5, correspondence G. Ainsworth Harrison to W.B. Fagg, 7th March 1962.
55 Schaffer, “‘Scientific’ racism again?”, 269.
which left him ‘few Jewish fans’ by the end of his life. A feature of this was Gates’s limited sympathy for the victims of the Holocaust, and Škerlj’s letter also alleged that Gates, upon receiving his resignation, had insinuated that Škerlj’s ‘harrowing experience’ in Dachau concentration camp had affected his ‘mental outlook’.

Lehmann himself had lost family in Holocaust, and had avoided returning to Germany for many decades after his departure in 1936.

Lehmann’s loyalty to Gates is hard to account for, but the critical difference between Gates and Gayre may have been their scientific credentials. Gates was a scientist who had attained much success during his career – a fellow of the Royal Society, he held a chair in biology at Kings College London for two decades, and had been a research fellow at Harvard until 1957. Despite his ignominious dismissal from Howard University, his opposition to interracial relationships in his 1929 work Heredity in Man, and the content and agenda of Mankind Quarterly, Gates’s past institutional and academic approval continued to protect him. Likewise, Lehmann was protected by his own scientific credentials, and by the wider field of blood research. Jenny Bangham, in her work on Arthur Mourant and his blood group research, writes that it offered ‘a methodology for reforming human heredity’ to these scientists. Its appeal lay partly in the fact that though blood group frequencies varied across populations, all blood groups could be found everywhere, ‘neatly affirming both the notion of racial difference and the unity of mankind’. The clarity of distinct and demonstrable haemoglobin types and the necessity of laboratory expertise gave credibility to the study of SCA and other abnormal haemoglobins.

This area of enquiry derived its research questions both from the emerging discipline of molecular genetics and the older disciplines of anthropology and race science. Its practitioners, such as Hermann Lehmann, felt an affinity and friendship both with a select ‘old guard’ of field anthropologists and scientific racists, and with |

56 Ibid, 254.
60 Bangham, ‘What is Race?’, 94
younger generation of biochemists and haematologists. These social connections shaped both his research and his career opportunities. In the same year as Lehmann was acting as a go-between for the RAI and Gates, he applied to the Medical Research Council to set up an ‘Abnormal Haemoglobins Unit’ devoted to researching and cataloguing haemoglobin variants in humans. Among his referees were his friends Max Perutz, an Austrian emigré who the year before had won the Nobel Prize for Chemistry for his work on the molecular structure of haemoglobin, and Arthur Mourant, head of the MRC Blood Group Reference Laboratory in London.\(^{61}\) They declared that his research was of the utmost importance, and relevant to their own work and to developments in the international community. His application was successful, and the MRC Abnormal Haemoglobins Unit came into being in 1963.

‘Unknown origin’: Defining populations in the Abnormal Haemoglobin Unit

The MRCAHU ran for almost fifteen years, from 1963 to 1977, after which the MRC withdrew its funding. The World Health Organisation designated it an International Reference Centre for Abnormal Haemoglobins in 1965, and agreed to make financial contributions towards future work.\(^{62}\) In this period, Lehmann amassed a massive collection of abnormal haemoglobin specimens through an extensive global network of doctors and researchers – a product of the blurred research and service functions of the Unit. Researchers sought clarity on blood samples taken in the field by sending them to the MRCAHU, and possibly also hoped to catch the great man’s

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\(^{61}\) Letter, A.E. Mourant to B.S. Lush, ‘In confidence’, 10 December 1962, and Letter, M.F. Perutz to B.S. Lush, 6 December 1962, TNA FD12/89. It was noted in the MRC files that his application was approved ‘in view of the excellent impression made by Lehmann in his Noon Session talk... and of the very favourable opinions expressed by referees’. Office note, ‘Application of Dr H. Lehmann for the establishment of a research unit on abnormal haemoglobin’, 3 January 1963, TNA FD12/89.

eye. But the Unit also received samples from British doctors who were encountering migrants – often from the former empire – in their clinics. Where hospital pathologists and laboratories were not equipped or trained to test these samples for abnormal haemoglobins, these samples were sent to Cambridge. The MRCAHU’s operations coincided with a period of high Commonwealth migration into Britain, and Britain’s medical personnel were seeking information and support in treating these ‘newcomers’. Jordanna Bailkin has shown that social anthropologists such as Kenneth Little, Michael Banton and Sheila Webster became experts on Commonwealth migrant communities within Britain during this period. The MRCAHU’s service requirements meant that its personnel were called upon to become experts on the haemoglobin of these migrants. At the same time, as physical anthropologists and geneticists, their research aims were frustrated by migration to Britain. This section will explore these blurred lines between the clinic and the field through an analysis of the MRCAHU casebooks – in which samples sent to the Unit were logged – and publications. Samples would be taken and sent for analysis, and the resulting sample slides would often be exchanged between scientists to compare technical methods and pathology.

Within such global population surveys, particularly of blood, geography was central to the classification of these samples. As Susan Lindee has shown, ‘hereditary material in post-war human genetics was deeply geographical even when it was on its own, isolated from the people to whom it belonged’. Tensions over the meaning of race and racial difference were embedded in these geographical meanings. This section will find that as researchers attempted to situate their samples (and the people they belonged to) in space, they were also trying to situate them in time, treating haemoglobin as a historical archive in which a stable set of populations could be observed. The 1952 UNESCO statement, entitled The Race Concept: Results of an inquiry had concluded that

Existing races are merely the result, considered at a particular moment in time, of the total effect of [natural selection, mutation and intermarriage] on

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64 Lindee, ‘Scaling up,’ 189.
the human species. The hereditary characters to be used in the classification of human groups, the limits of their variation within these groups, and thus the extent of the classificatory subdivisions adopted may legitimately differ according to the scientific purpose in view.65

Like its predecessor, the statement took the view that separate ‘races’ were a biological reality that did not map onto cultural, religious or national groups. Races existed, but disappeared once definitions were approached. ‘Even the major groups’ – which the statement avoided naming, unlike the first statement – ‘grade into each other, and the physical traits by which they and the races within them are characterized overlap considerably’.66 Significantly, this statement defended scientific investigations into racial groups and ‘hereditary characteristics’. This ambiguity about the significance of both genetic traits and social groupings for ‘race’ can be found in the methodologies of contemporary scientific investigations. The research conventions and questions asked by the MRCAHU reflect the approach of the broader scientific community, who emphasized the fluidity of racial difference whilst also seeking to stabilize it as a concept.

The Lehmann collection, held in the Whipple Museum of the History and Philosophy of Science in Cambridge, holds twenty-one casebooks containing records of the blood samples (and the people these were taken from) sent to the MRCAHU between 1961 and 1985. They were a research tool central to the process of gathering information, and developing knowledge, about the global distribution of abnormal haemoglobins. Each entry records the date the sample was received, a unique reference number, the name of the referring physician and the address of their institution, the patient’s name and age, and the results of the tests conducted on the person’s blood samples. Entries were ticked by the lab technician and dated again when the results were reported back to the referring physician. The time lag between receipt of a sample, its testing and its subsequent reporting varied between two days and a fortnight. The reference numbers related to, and ordered, the physical samples preserved in the lab, tethering the blood to its written profile — a

66 Ibid, 12.
combination essential for the significance (or insignificance) of the sample to be determined. These casebooks are the artefacts of the MRCAHU’s ‘service element’, which Lehmann was at pains to emphasise in his progress reports to the MRC was ‘linked to [the Unit]’s pure research, and many of the new haemoglobin variants came to it because an outside laboratory sent a sample of blood for advice’.67

Field researchers and doctors sending these samples to the MRCAHU often assigned them an ethnic label. Table 1 illustrates some examples of descriptions accorded to these samples from the casebooks and how they might be broadly categorized. The ambiguity of some of these terms makes categorization difficult and sometimes crude. Superficially, some fit easily into categories, such as nationality or religion, but some could easily describe both a linguistic group and an ethnicity, such as ‘Sindhi’, or a tribal identity and an ethnicity, such as ‘Bedouin’.68 This is unsurprising given that many of the personnel assigning these labels may have found the flexibility of these terms useful, and intended them to convey more than one category. For the purpose of broad data analysis however, the heterogeneity of the terms found in the casebooks require a ‘tagging’ system in order to observe some broad trends over time. Several categories are geographical, linked to sub-continental, national and sub-national regions. Others can be defined as more closely relating to identity, such as religion, ethnicity and tribal descriptions. I have taken those linked to skin colour to be ‘racial’, although historically which groups count as ‘races’ has been highly contingent – American immunochemist W.C. Boyd (1903-83) described thirteen races in seven groups, including European, African, Asian, Indonesian and Melanesian ‘races’; while Stanley Garn described nine ‘geographical’ races and thirty-two ‘local’ races.69 Finally there are the epithets that explicitly give more than one origin point or type of information. ‘Dual nationality’ terms attempt to describe a person of mixed heritage; the ‘hybrid’ category incorporates two or more of the previous categories such as religion and place of

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birth (such as ‘Sikh born in Punjab’); while the ‘linear migration’ category I have used for those which describe more than one origin point (more on this below).

In the casebooks, descriptions of patient origins take the form of written notes next to the patient’s name and age. To better analyse long-term trends in this type of editorialising, I have taken four sample years from the MRC casebooks – amounting to over 1,200 individual cases – and entered the anonymised data into a database for quantitative analysis. These ‘origin’ descriptions occur in varying rates, year to year, but 98% of these descriptions relate to non-British identities. It is unlikely that this category was part of a standard blood sample submission form, as many samples accompanied by clearly non-British names were frequently not editorialised with geographical epithets. The most likely explanation is that this was information volunteered by the referring physician or researcher, and subsequently deemed significant by those who received the sample in the MRCAHU. In November 1969, one Mr M.T. Donnan of Dudley Road Hospital in Birmingham sent a blood sample he labelled ‘Negress’ to the laboratory, which was subsequently analyzed as positive for sickle cell-haemoglobin C disease. Commonly the descriptions were of Commonwealth nationalities, such as ‘West Indian’, ‘Nigerian’ and ‘Pakistani’ were provided alongside suggestive symptoms like ‘jaundiced’, ‘swollen [left] thigh’, or ‘anaemic’. Referring physicians considered patient origins to be medically relevant, and perceived a non-British origin as a diagnostic red flag, at least when it came to blood. Though on average 25% of samples came from outside of the UK, these geographical descriptions were rarely used with non-British samples (see Chart 1). The few samples sent from non-British locations with such ‘origins’ descriptions were other European countries such as Switzerland and Denmark, or former British colonies such as South Africa and Canada. These epithets of origin are an unusual insight into how British doctors and other health professionals perceived the patients before them, and how they framed populations and origins. British doctors were acting as field researchers as well as clinicians – if the service and research functions were blurred, it was because in practice the field and the clinic also shaded

70 Of the total 297 samples that were editorialised with an ‘origins’ description from the sample years analysed, only six were designated ‘English’, ‘Irish’, ‘Welsh’ or ‘British’.
into one another. As we will see, however, the MRCAHU struggled with these ambiguities.

Physicians referring samples to the Unit frequently conveyed the complexity of the provenance of the blood through these descriptions, sometimes giving multiple points of origin to convey the possible vectors of any abnormal traits. For example, a sample taken in October 1969 at Addenbrooke’s Hospital in Cambridge, indicating thalassaemia, was labelled ‘of Indian extraction to Tanzania’.\(^{72}\) In another case, a SCA-positive blood sample taken in August 1964 in Brook General Hospital in Woolwich was annotated ‘West Indian of African extraction’.\(^ {73}\) A sample sent from the Millbank Royal Army Medical Corps was listed as ‘South American by birth. Serving in Germany’.\(^ {74}\) One Dr. G.L. Robinson at the Greenwich Seaman’s Hospital sent a total of twelve samples in 1964 labelled ‘Chinese from Hong Kong’.\(^ {75}\) Some samples hint at conversations between doctor and patient, in which doctors had asked – or the patient had volunteered – where they came from. Others are less detailed and suggest an assumption made by the physician on the basis of appearance – particularly blunt racial descriptions such as ‘coloured’ or ‘Negro’. Such examples gave not just the migration history of the individual, but privileged the patients’ ancestral history of migration as being of clinical interest. Intermarriage was considered important in casebooks as well – a woman with raised A2 haemoglobin, often an indicator of thalassaemia, was labelled the ‘Mediterranean wife of an Englishman’,\(^ {76}\) another ‘Father Indian from Hyderabad, Mother English’.\(^ {77}\) This hereditary material was ‘deeply geographical’ and here we see the depth of that geography, fused with the medical genetics practice of family histories and tracing the geographical ‘route’ of the trait under discussion. These blood samples were endowed with multiple explicit and implicit narratives of migration, as doctors and technicians tried to make sense of the emerging literature about SCA and its associated conditions, and the patients in their wards and clinics. These samples


\(^{73}\) CR64-647, 20 August 1964, MRCAHU casebooks, Whipple.

\(^{74}\) CR69-1378, 28 June 1969, MRCAHU casebooks, Whipple.

\(^{75}\) CR64-15, 64-25, 64-171, 64-206, 64-256, 64-458, 64-540, 64-563, 64-574, 64-607, 64-695, 64-771, between 14 January 1964 and 10 October 1964, Whipple.

\(^{76}\) CR73-917, 2 June 1973, MRCAHU casebooks, Whipple.

\(^{77}\) CR69-1641, 9 September 1969, MRCAHU casebooks, Whipple.
and their labels also indicate that British physicians were recruited as field
researchers into a broader project of ‘race science’.

There was a notable shift over time in terms of the choice of terminology used
in the casebooks. Chart 2 shows a breakdown of the varying frequencies of the
different description types over time. The most prominent trend emerging from this
data is a consistent increase in terms relating to ‘nationality’. In 1964 these
accounted for 50.62% of descriptions, and this increased slightly to 51.43% in 1969.
By 1974, 58% of descriptions were exclusively of nationality, and this continued to
grow to 62.79% in 1979. 1979 also sees a jump from 4% of descriptions with a sub-
national region to almost 13.95%. More generalised ‘continental’ descriptions such
as ‘African’ also declined. Over time, it appears that the scattered community of
doctors who were sending these samples to the MRCAHU began to adopt a more
consistent framing for their ‘origins’ descriptions, increasingly preferring national or
geographical terms. Might this be a sign of growing consensus on what might
constitute medically relevant information about a patient’s ‘origins’, or at least on the
best terminology to convey these origins? When contextualised against the 1952
UNESCO statements on race discussed above – the first supported by sociologists
and social anthropologists, and the second formulated in response by biologists and
physical anthropologists – this trend is curious. The first statement sought to ‘shift
attention away from the term ‘race’ and focus instead on… culturally-determined
‘ethnic groups’”, while the second claimed that ‘race’ was ‘a biological concept that
should not be confounded with national, religious, or cultural groupings’.78 Though
the latter disagreed with the former on the analytical utility of ‘race’ as a category,
both camps agreed that national, religious and other ‘social’ groupings could not map
onto ‘racial’ ones, and vice versa. The rise in the use of national descriptions in the
MRCAHU casebooks suggests that, for the medical personnel collecting data on the

Table 1: categorisation of samples

<table>
<thead>
<tr>
<th>Tag</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Religion</td>
<td>‘Sikh’, ‘Jewish’</td>
</tr>
<tr>
<td>Sub-continental region</td>
<td>‘West African’, ‘West Indian’, ‘Arabian’</td>
</tr>
<tr>
<td>Linear migration</td>
<td>‘Indian descent domiciled in W Indies’, ‘South American by birth. Serving in Germany’, ‘of Indian extraction to Tanzania’</td>
</tr>
</tbody>
</table>
ground, this distinction was difficult to apply when defining populations for genetic investigation.

Elazar Barkan has argued that, before 1945, British anthropologists ‘blurred’ the specific ethnicities of black people into a homogenous whole. He attributes this tendency to the separation between colony and metropole, unlike the United States. The same may well have applied to the doctors and technicians sending these samples, and the slow transition away from generic racial descriptions towards geography and nationality might reveal a burgeoning understanding of the multiplicity of black identities, in tandem with increasing decolonisation and independence in Africa. Some physicians may also have found nationality to be a ‘value-free’ terminology for hinting at a patient’s ancestral ‘origins’ without exposing themselves to accusations of racism. In the disciplines of anthropology and sociology, British scholars investigating the effects of migration had also rejected terms such as ‘Negro’ early on. The American anthropologist Ruth Landes was informed by a British psychologist when she undertook research in British urban centres in 1951-52 that ‘there are no ‘Negroes’ in Britain, no ‘coloured’ – we just don’t think that way. We think of men from Jamaica, and from the Gold Coast, and from Barbados – not so-called Negroes’. Bailkin has argued that British experts were conscious of the state of ‘race relations’ in the USA, and proud of the absence of a legal colour bar in Britain. An increasing, if tentative grasp of the politics of race among these referring clinicians may account for the expurgation of racial terms from their clinical language, though they continued to sort their patients into distinct and separate groups.

If these physicians considered ancestry to be clinically relevant in sending these samples to the MRCAHU, then the Unit and the publications that emerged from it employed SCA as an ‘ethnological tool’ to answer questions about migration, racial ‘purity’ and tribal history. Tapper observes that the blood workers who studied SCA during the 1940s and 1950s used the disease as a vantage point onto ‘black history’. To render abnormal haemoglobins as a legible ‘genomic archive’,

79 Barkan, Retreat of Scientific Racism, 23.
80 Ruth Landes quoted in Bailkin, The Afterlife of Empire, 32.
81 Bailkin, The Afterlife of Empire, 31.
82 Tapper, In the Blood, 58.
however, much work had to be done the untangle the migration histories of the blood sample donors. Migration ‘was one of the first issues that postwar experts were called upon to manage and define… who themselves vigorously debated how to interpret the population transfers taking place around the globe’. In British immigration policy, ancestry and migration became crucial tools for the conceptualisation of British citizenship. The best example is the notorious 1968 Commonwealth Immigrants Act, which restricted right of entry to the UK to those born there, or who had at least one parent or grandparent born there – a clause defended as ‘geographical and not racial’ by its supporters.

In publications authored by Lehmann and his colleagues, family histories were used to trace not only the inheritance of traits through generations, but were closely geographically referenced to trace the movement of these generations across continents. Furthermore, this geographical positioning and search for the ‘true’ origin point of an abnormal haemoglobin trait was essential to demonstrate its significance. In one 1957 British Medical Journal study entitled ‘Haemoglobin K in an East Indian and his family’, Lehmann and his co-author carefully situated their findings as novel, although Haemoglobin K had been observed before. Crucially, Haemoglobin K had previously been found only in ‘Berbers’, Liberians, and the ‘Dagomba tribe’ of Northern Ghana. Surveys of abnormal haemoglobins in East Indian populations had so far yielded only Haemoglobins S (sickle-cell), D and E. The authors were therefore at pains to demonstrate that their subject is East Indian:

The subject of the present investigation, an Indian resident in London, was born in South Africa, where his grandfather had immigrated from India (Madras). Though he married a woman of Scots and West Indian origin there is no evidence in his appearance or from his family history that there has been any admixture of non-East Indian blood amongst his own ancestry… As he was a non-European he was examined for abnormal haemoglobin.

83 Bailkin, The Afterlife of Empire, 24.
That this family history mapped onto a migration history – tracing the propositus back from London to South Africa to Madras across three generations – was reinforced by the evidence of ‘his appearance’ that there had been no ‘admixture of non-East Indian blood’. Implicit in this is the deployment of typological methods, likely comparing the man’s skin colour and facial features to that considered typical for East Indian people. This was not necessarily unusual for the period – though anthropometric methods had been criticized since the late nineteenth century, it remained a credible scientific approach until the 1960s. In 1964, a WHO expert group recommended both blood samples and measurements when studying ‘population genetics of primitive groups’.  

That even the man’s marriage was considered relevant in the investigation of his background is revealing of broader scientific anxieties when attempting to isolate populations. In a peculiar passage, the authors were careful to stress that even though he had chosen a woman who was not East Indian but of mixed origin, ‘amongst his own ancestry’ there is no evidence to suggest that he is similarly mixed – as if his choice of a wife of ‘Scots and West Indian origin’ might suggest a preference for ‘admixture’, explicable by a possible mixed ancestry of his own. In another article discussing where Haemoglobin D variants have been found, examples include ‘an English woman married to a Negro’ – another instance of interracial marriage being considered clinically relevant for the spouses, as well as for their offspring.  

Ann Laura Stoler writes that ‘colonial administrations were prolific producers of social categories,’ and her work on colonial archives examines them as ‘condensed sites of epistemological and political anxiety rather than as skewed and biased sources’. In the MRCAHU publications we can discern anxieties about the integrity of ‘isolate’ populations, and also about the implications of ‘admixture’ between migrant newcomers and the established population of Britain.

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86 Lipphardt, “Geographical Distribution Patterns of Various Genes”, 52.
This interest in purity and admixture within the population of Britain was made explicit in a 1965 article for *The Journal for the Royal Anthropological Institute of Great Britain and Ireland*. Lehmann and his co-authors described an unexpected result: a haemoglobin ‘identical’ to one found in the Punjab had been found in a Norfolk family. This haemoglobin had also been discovered in ‘a Portuguese, a Cypriot, and two white Americans’. Notwithstanding this, the authors decided to consider the evidence that this Haemoglobin D\textsubscript{b} Punjab was introduced into the East Anglian family ‘directly’. It went on to consider historical sources speculating about the likelihood of legitimate or illegitimate children being born to liaisons between Indian women and British troops stationed in India or as a result of intermarriage between Indian servants brought to Britain and ‘the native English population’. These sources included the 1824 military regulations under the Presidency of Calcutta, memoirs of servants of the East India Company, the correspondence of Cornwallis, and the ecclesiastical records of the churches of Madras. The authors noted that the propositus and his family ‘appeared to be of pure East Anglian stock’. Another article on an abnormal haemoglobin in a Norfolk family noted that the family was ‘of Norfolk farming stock and so far as they are aware they are purely English’. Nowhere in these contorted explanations was the possibility of spontaneous mutation mentioned, for to do so would be to undermine the promise of haemoglobin analysis for revealing history. The article concluded with a prediction that future surveys of Europeans would find haemoglobin D\textsubscript{b} Punjab in France and Portugal as well as Britain, reflecting the imperial involvement of these countries in India’s history.

This focus on origin points and geography, incorporated into layers of family history, was reflected in the naming practices for new haemoglobin. But this practice of nomenclature in itself reveals tensions between sample origin points and the ‘true’ origin of the patient. The complex provenance of blood made naming each haemoglobin difficult. Initially haemoglobins were simply named with letters, but as

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89 Konigsberg et al, ‘Haemoglobin D\textsubscript{b} Punjab in an East Anglian Family’, 304.
90 Konigsberg et al, ‘Haemoglobin D\textsubscript{b} Punjab in an East Anglian Family’, 295.
92 Konigsberg et al, ‘Haemoglobin D\textsubscript{b} Punjab in an East Anglian Family’, 304.
more and more were discovered this practice became unsustainable and so haemoglobin variants were increasingly named after the locations in which they were discovered. Sometimes the person’s profile was seen to fit the location, in the case of Haemoglobin Beilinson which was discovered in an Ashkenazi Jewish family in Beilinson Hospital in Israel, and the discovery would be happily and uneventfully logged. But sometimes researchers found the sample and its location to be incompatible. Lehmann himself puzzled over this:

We considered it somewhat incongruous for an insignificant haemoglobin fraction to be called ‘Hb London’, particularly since this fraction was discovered in the baby of a Spanish father and a Chinese mother from the West Indies… In the end, the variant was called ‘Hb Bart’s’ after the hospital.

Here the nomenclature was confused by the mixed parentage and migration status of the child. Lehmann considered designation by the metropolis of London misleading and inappropriate. In other new variants, the person’s place of birth had sufficed – a new haemoglobin found in a woman who presented at a hospital in Nairobi was named Haemoglobin J Nyanza, after the woman’s place of birth 300 miles to the west. When a previously unknown haemoglobin was discovered in a young Englishman living in Singapore, it was named Haemoglobin Norfolk after his place of birth. However, for this child, born to parents from Spain and the Caribbean, its birthplace in London in 1958 was considered too ‘incongruous’ for the fraction to be named after the country’s capital. ‘Hb Barts’ appealed instead, either because of its location in London’s East End, which had been home to migrant communities for centuries, or because the researchers perceived hospitals as an

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international medical space with no geographical or racial connotations, even if it was a last resort. As C.L.R. James said of Caribbean migrants to Britain, they were ‘in, but not of, Europe’. 98

Not all of these haemoglobin ‘discoveries’ have stood the test of time. As technology improved following the development of techniques to isolate and analyze chains of amino acids, meaning exact abnormalities could be pinpointed, it was discovered that many of these distinct haemoglobin types were actually the same. 99

The methods of the MRCAHU served to create differences, which as they emphasized diversity also undermined the notion of human relatedness. Though migration was recognized as a natural part of the fluidity of human relatedness, in practice researchers sought to make meaning of traits by tracing them back to parents or grandparents. Despite these assumptions about stable and concrete populations, the discoveries of the MRCAHU team emphasized the similarities across different populations. Like blood groups, though frequencies of haemoglobin types varied between groups, single traits could be found in many different groups. For the Unit, a publishable discovery was not just a new haemoglobin variant, but also the detection of an existing variant in a new population. By the 1970s, many MRCAHU publications would begin with a preamble detailing the many populations in which the variant under discussion had been discovered. Lehmann saw the political relevance of such a detail, as evidenced by his involvement in a 1971 controversy following a British Medical Journal article proposing that ‘all passengers and aircrew who might have some form of sickle-cell disease should be screened before flight’, due to the risk of sickle cell ‘crises’ in unpressurized aircraft. 100 When the press, in reporting this story, described sickle cell as ‘a hereditary disorder of the blood that affects Negro populations’, Lehmann was swift to push back against this generalisation. 101 In a letter to the Times he explained that the sickle cell trait is, in some Africans, ‘much more rare than in the population of say Crete or

Coimbatore’. As well as detailing the spread of haemoglobin mutations beyond a single geographical region or population group, speculation about past migration habits in MRCAHU populations occasionally brought the empire’s history ‘home’. Genetic recognition of intermarriage between British military and Indian women, ‘confirm[ing] the bonds that existed between these countries and India between the 17th and 20th centuries’, was significant in the context of 1970s Britain in which government and popular discourse framed Commonwealth migrants as ‘strangers’, rather than as a people with whom Britain had a long and involved history.

Within the wider project of population genetics, finding multiple haemoglobins in multiple populations, the workers’ methodologies served to substantiate concepts of distinct races. As they pursued the ‘true’ origins of their subjects and samples, attempting to peel away the effects of recent ‘immigration’ to reveal historical ‘migration’, as they scanned the physical appearances of their subjects for signs of intermarriage in their ancestries, so the research they produced assumed the existence of concrete ‘races’. The slippage within the usage of the term ‘blood’, as in the article which stated that the propositus had no ‘admixture of non-East Indian blood amongst his own ancestry’, is especially interesting. They were not testing blood as a whole but specifically the haemoglobin within blood cells, and yet blood as a metonym for ‘race’ and family frequently slipped into discussion of results obtained by the MRCAHU. The use of terms such as ‘admixture’, and ‘ancestry’ to describe a racial type situates Lehmann, in Tapper’s words, ‘at the intersection of modern genetics and the new physical anthropology on the one hand, and eugenic genetics and racialist anthropology on the other’. But Lehmann’s work must be read within a postcolonial British identity crisis. He labelled migrants and their children with their ancestral ‘origins’ and struggled to locate them in the British metropole, even as he also articulated genetic evidence for British colonization and the familiarity of colonizer and colonized. There was a tension between the casebooks of the MRCAHU – which recorded an enormous number of samples

105 Tapper, In the Blood, 42.
labelled with various non-white identities, sent from British clinics – and the Unit’s research agenda and outputs, which focused on overseas research. This tension exemplifies the status of Commonwealth migrants to Britain as ‘familiar strangers’. They were resident in Britain, very often British citizens with a deep historic connection to the metropole, but nevertheless perceived as essentially ‘of’ somewhere else.

From the field to the clinic: Sickle cell comes ‘home’?

Soraya de Chadarevian argues that Lehmann’s collection of abnormal haemoglobin functioned as a boundary object in ‘the circulation of tools and practices’ between institutional sites, which was particularly valuable in the absence of clinical application of molecular genetics.106 These samples facilitated the circulation of tools, practices and expertise on blood and haemoglobin, particularly between the United States and Britain, and between the clinic and the laboratory. Elise Burton has argued that local workers were ‘essential collaborators’ in this exchange, but that their contributions often went unacknowledged.107 This section will show that this collection, and the process of collecting it, functioned as a boundary object situation in a postcolonial network – transferring resources, training and power between local workers in former colonies and elite basic researchers located in scientific metropoles. The collection of abnormal haemoglobins became an agent by which these essential collaborators were reframed as recipients of postcolonial ‘international development’. Though Bivins has argued that tropical medicine ‘came home’ with its practitioners at the end of empire, the deeply geographical interpretation of genetic material in this period, coupled with a reluctance to see Commonwealth migrants as permanent settlers, meant that the research ‘field’ did not come home so decisively.108

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108 Bivins, ‘Coming ‘Home’ to (post)colonial medicine’. 
In 1957 – five years before the establishment of the MRCAHU – an ‘Abnormal Haemoglobin Seminar’ took place in Istanbul. The conference had originally been proposed in early 1956, as one in a jointly-funded programme of symposiums between the Council for International Organizations of Medical Sciences (hereafter CIOMS – a sub-division of the World Health Organisation and UNESCO) and the Rockefeller Foundation. Searching for a subject that would encourage ‘research and its application in countries less scientifically advanced than North America and Europe’, the Secretary-General of CIOMS suggested something centred around ‘blood groups, sickling, abnormal haemoglobins etc in the population of Africa’. In his earliest pitch, he envisioned that the meeting would have ‘a strong ethnological flavour and might throw light on many unsettled questions’.\(^{109}\) In subsequent iterations of the conference programme, the delegates were tiered into Western experts and local scientists, and the relationship between them was clearly intended to be didactic. By early 1957 plans for the symposium had begun to take shape: ‘the local workers will constitute the audience and mingle with the senior people outside the working sessions’, with an additional ‘practical’ seminar to take place afterwards for the benefit of these local workers.\(^ {110}\)

The five-day conference took place in Istanbul in September 1957, with three of the five sessions ‘devoted to the geography of the haemoglobins’ and their significance for the study of past migration and understanding of racial groups. The following week, the Dutch haematologist J.H.P. Jonxis wrote to Maier to thank the Rockefeller for the $10,000 contribution towards costs and to report his impressions of the event. ‘It has made exchange of thoughts possible between people from different countries,’ he wrote:

> especially between Asia and Africa where the abnormal haemoglobins mainly occur and Europe and U.S.A. where most of the theoretical work is done... At the same time the symposium has showed us how wide the gaps in our knowledge still are especially in the practical field. This is caused, in my

\(^{109}\) Letter, J.F. Delafresnaye to Dr Maier, 17 January 1956, Box 25, 100-100.D, Series RF 1.2, Rockefeller Archive Center, New York.

\(^{110}\) Correspondence J.F. Delafresnaye to Dr Maier, 4 January 1957, Box 25, 100-100.D, Series RF 1.2, Rockefeller Archive Center, New York.
opinion, by the large distances between the scientific centers and the places where these abnormalities are common.\textsuperscript{111}

This symposium illustrates the ‘centres’ and ‘peripheries’ involved in the study of SCA, and is a snapshot of emerging relationships between ‘local workers’ and ‘senior people’ at this time. Local workers were required to leverage their access and proximity to haemoglobin variants and haemoglobinopathies to gain credibility within the international research community. One month before the conference took place, Dr. L.D. Sanghvi, the chief of the Human Variation Unit at the Indian Cancer Research Centre in Bombay, wrote to the Secretary-General of CIOMS. While visiting Dr. Hermann Lehmann in London, he wrote, he had heard there was a chance that his research assistant P.K. Sukumaran could be invited to the symposium. He explains that haemoglobinopathies have been found in southern India, and that

if the principal worker on this subject in my Department could at this stage have the benefit of contact with the leading workers in the field and in particular have direct technical instructions and advice – it would be of outstanding help.

He then emphasized that Bombay is ‘quite a centre of research these days, nevertheless in a special field like the haemoglobinopathies we are entirely isolated’.\textsuperscript{112} Lehmann’s involvement in this invitation was not a coincidence – he had met Sukumaran (known affectionately as ‘Suku’) while on a field trip to Coonoor in 1951. Sukumaran, then at the Pasteur Institute in the Nilgiri region, had provided technical help and ‘friendship’ and was ‘eager to learn how to do sickling tests and blood grouping’.\textsuperscript{113}

After some negotiation over funding, Sukumaran and 17 other scientists (primarily from Turkey but also including representatives from Lebanon, Jordan, Iraq,

\textsuperscript{111} Correspondence J.H.P. Jonxis to Dr Maier, 3 October 1957, Ibid.
\textsuperscript{112} Correspondence L.V. Sanghvi to J.F. Delafresnaye, 13 August 1957, Ibid.
\textsuperscript{113} Dacie, ‘Hermann Lehmann’, 417.
Egypt and the Sudan) were the audience to the 24 Western scientists who presented their conclusions. They then received technical training in laboratory skills pertaining to the haemoglobins.\footnote{114 ‘Liste des Participants – Colloque sur les hemoglobines abnormales’, Rockefeller Archive Center, New York.} In the following decades, Sukumaran sent multiple consignments of blood samples from Bombay to Cambridge, and several of these samples were subsequently published. In 1972 the \textit{British Medical Journal} published an article authored by Sukumaran and Lehmann on ‘Haemoglobin Q India’, an abnormal haemoglobin now discovered for the first time in ‘3 Sindhi-speaking Hindu families with children suffering from \(\beta\)-thalassaemia major’, who had been admitted to the Jerdia Wabia Hospital in Bombay.\footnote{115 P.K. Sukumaran, S.M. Merchant, Menna P. Desai, Barbara G. Wiltshire, and Hermann Lehmann, ‘Haemoglobin Q India (alpha64(E13) Aspartic Acid - Histidine) Associated with Beta-Thalassaemia Observed in Three Sindhi Families’, \textit{Journal of Medical Genetics} 64 (1972): 436–42.}

Sukumaran was a helpful friend to Lehmann, as was the Ghanaian physician Felix Konotey-Ahulu. In the late 1960s, Konotey-Ahulu sent Lehmann a haemoglobin variant from Accra, which he was able to compare to another sample he had been sent. Upon a visit to Konotey-Ahulu’s clinic in Accra, Lehmann collected a third sample which allowed him to conclude that ‘Hb G Accra was identical with Hb Korle Bu, and the reason it had been missed on the first occasion was that the amide group of that particular asparagine was highly labile.’\footnote{116 Lehmann and Schneider, ‘Hemoglobins we have known’, 475.} For his part, Konotey-Ahulu proudly cited the patronage of figures such as Lehmann in the many retrospectives he has written of his medical career. In 2009, he recalled that Lehmann not only joined Professor Bela Ringelhann and me in Ghana for countrywide surveys and lectures in Ghana but he also sent his trusted laboratory technician Pamela Kynoch to us to standardize our techniques… The Secret of Success of the work in Ghana was the way these expatriates encouraged full Ghanaian participation in the research process.\footnote{117 F.I.D. Konotey-Ahulu, ‘Clinical Genetics: Ghanaian Gratitude for British and Hungarian Contributions: A Personalized Historical Perspective,’ \textit{Ghana Medical Journal} 43:4 (2009): 175–78.}

Konotey-Ahulu understood his own cooperation as essential to haemoglobin research in Ghana, and saw Lehmann’s collaboration and encouragement as crucial.
to his own contribution. However, Konotey-Ahulu also countered Western biomedical knowledge of SCA – challenging notions of homogenous African nations and tribes, refining Lehmann's anthropological theories with his own understanding of West African oral traditions, and rejecting the explanation of SCA as a balanced polymorphism on the grounds of his Christian evolutionary scepticism.¹¹⁸

Throughout his career Lehmann established relationships with local workers that could give him access to desirable populations. He secured training for these workers, both through conference attendance and loaning his own laboratory technicians. The result was that, as one of his collaborators noted that ‘the number of hemoglobins with which Hermann Lehmann has been associated is so vast that comparison makes mine, and everyone else’s, seem picayune.’¹¹⁹ The MRCAHU casebooks enable further investigation into the network that enabled such research. In the years examined, a quarter of the blood samples sent to the MRCAHU were sent from overseas, often from former British colonies. These overseas samples, moreover, made up much more than 25% of the Unit’s research output. Articles published by the group frequently referred to samples taken from patients in hospitals and field situations around the world. The casebook data reveal relationships and networks on a layer of expertise separate from colonial administration and international diplomacy. Statistical analysis of the samples and the locations they were sent from enables an overview of the countries and locations with whom the Unit had relationships. Each consignment – even if it contained multiple samples – was counted as a single entry, so as not to distort the appearance of relationships by field trips, in which hundreds of samples could be taken. In all, 50 countries sent 127 consignments of blood during the four sample years – 37 in 1964, 54 in 1969, 31 in 1974, and only 5 in 1979. While the small sample size makes it difficult to extrapolate sweeping conclusions about the network, some anecdotal evidence within the dataset sheds more light on these trends. The


¹¹⁹ Lehmann and Schneider, ‘Hemoglobins we have known’, 479.
strong representation from Africa and Asia was probably due to British doctors on overseas postings with the Royal Army Medical Corps. Those from the United States and Canada reflect samples being exchanged between academics, commonly in departments of biochemistry and haematology. The poor representation from South America – despite the active molecular genetics community, particularly in Brazil – suggests that the infrastructure for Western infiltration of medical structures, such as the R.A.M.C., was a strong predictor for engagement with institutions such as the MRCAHU.

Looking closer at the data, Table 2 shows the ten countries outside the UK that sent the most consignments of blood over the four sample years taken. Though the sample sizes are small, and an overemphasis on ‘nations’ in this fluid network would be misguided, this table illustrates the variety present in the casebooks. The most prolific countries are a curious mix of European countries and former colonies, with the most samples coming from Italy, from institutions in Padua, Ferrara, Milan and Genova. South Africa sent the second most samples across the sample years, primarily from the same two researchers, Dr M.C. Botha and Dr Trefor Jenkins. Zambia, Sudan and Ghana – former British colonies – also featured heavily. The table offers glimpses into some of the Unit’s particular interests. Researchers in multiple institutions in Israel, from Jaffa to Tel Aviv to Jerusalem, sent to the Unit samples of possible ‘Haemoglobin Hasharon’ – a variant Lehmann was particularly interested in. Italy’s dominance reflects an interest both in the thalassaemias, and in the same Hb Hasharon that several publications began to trace across Europe and the Middle East. The strong showing of Switzerland can be accounted for by the World Health Organisation’s presence in Geneva. Over the course of the four sample years, the MRCAHU received 1249 consignments of blood samples, of which 1044 were from the UK. They processed 138 samples positive for the sickle

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120 L.A. Reynolds and E.M. Tansey (eds.), Wellcome Witness Seminar: British Contributions to Medical Research and Education in Africa After the Second World War (London, Wellcome Trust Centre for the History of Medicine, 2001).
121 de Chadarevian, ‘Following Molecules’, 186.
123 Lehmann and Schneider, ‘Hemoglobins we have known’: 482.
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cell trait, SCD or sickle cell beta thalassaemia sent from the UK, 44 of which were from London. In that time, they received one from the Caribbean. However, though Commonwealth migration to Britain meant that the incidence of these traits was increasing yearly, Lehmann and his colleagues continued to focus on sub-Saharan Africa, south Asia and the Middle East as the centre of their research. This is exemplified by Lehmann’s relationships with the South Africa-based geneticist Trefor Jenkins and the Liverpool-based haematologist David Weatherall in the early 1970s.

Jenkins had submitted multiple samples to Lehmann’s laboratory over the years.\textsuperscript{124} He collected these under the conditions of apartheid South Africa. South Africa was embargoed for scientific research by the WHO brought about by a coalition of African states, who petitioned the World Health Organisation (WHO) to suspend South Africa’s membership in 1964.\textsuperscript{125} Whilst working in the transfusion service of the South African Institute for Medical Research, he had access to the thousands of men from across sub-Saharan Africa who convened there to work in the gold mines. Blood donors ‘would give, or perhaps I should say, we would take (no consent was specifically given in those days!)… an extra 2 or 3 mls of blood at the end of collecting a pint for transfusion purposes and that gave me access to thousands of samples from dozens of tribal groups’.\textsuperscript{126} Some such samples were sent to the laboratory in Cambridge. It seems that Lehmann did not find their provenance offputting. Jenkins reflected that ‘although some people… wouldn’t come to South Africa because of the political situation, others didn’t feel that an issue at all.’ Lehmann was somewhere in the middle of this spectrum. Jenkins recalled that

\textbf{He was a consultant for WHO, so he didn’t want it to come out really that he was breaking the embargo on South Africa. So he did have some anxiety}


\textsuperscript{126} Jenkins, interview with Harper, 12.
about it but he overcame that somehow and had a great time, of course… He was relaxed and had a great time.\footnote{Ibid, 25-6.}

Lehmann and Jenkins together took a field trip into the Zambezi Region in 1973 – accompanied also by Lehmann’s wife – and co-authored a resulting paper on genetic lactose intolerance in the San people in the BMJ the following year.\footnote{T. Jenkins, H. Lehmann, and G. T. Nurse, ‘Public Health and Genetic Constitution of the San (‘Bushmen’): Carbohydrate Metabolism and Acetylator Status of the Kung of Tsumkwe in the North-Western Kalahari’, British Medical Journal 2:5909 (1974): 23–26.} He may have overcome his ‘anxiety’ about research in apartheid South Africa because of an edge he felt this offered him over Weatherall, who in that same year was lobbying DHSS to pay attention to the ‘acute clinical problem’ posed by SCD in Britain. ‘[H]e always liked to have one up on Weatherall, as you know,’ Jenkins said, ‘and to have a paper describing field work like that was something he felt Weatherall didn’t do!’\footnote{Jenkins, interview with Harper, 25-6.} Weatherall was twenty years younger than Lehmann, but Lehmann had jealously guarded his research area from their first meeting – telling Weatherall in 1960 that he ‘shouldn’t continue in this field because there was nothing left to do’, even as he was seeking funding from the MRC for his Unit.\footnote{Weatherall, interview with Harper, 4.}

Lehmann’s carefully cultivated remote access to the ‘field’ began to dwindle in the 1970s. By 1979, samples sent from outside the UK had decreased to almost nothing. Lehmann had officially retired in 1977, minimising the incentive to send samples in order to gain contacts or curry favour with the great man. Furthermore, the laboratory had been a World Health Organisation-designated abnormal haemoglobin reference centre since 1963. In the mid-1970s, the WHO designated several more of these reference centres, including in Ghana and in Madras, decreasing the demand on the Cambridge unit – so this drop may also be the result of new hubs emerging in the international genetics community, and a decreased reliance on the metropolitan expertise of the MRCAHU.

been key to forging colonial expertise, that ‘the violent realities of conquest made the pretense of political neutrality and the altruism offered by lay experts... both difficult to sustain and highly desirable’. In the dying years of formal empire the postcolonial laboratory worked to maintain ‘the fraudulent charisma of imperialism’, and to take advantage of the intellectual opportunities offered by the end of empire. Expertise ‘offered new ways to mediate relations between individuals and states, as well as competing visions of Britain’s changing role in the world’. Moreover, with the advent of the Cold War a ‘political language of moral superiority and capital development’ was essential to Britain’s global role going forward. Lehmann’s final word on his career enshrined his Cambridge laboratory as a convivial, multicultural space of learning. In his retirement letter to the Medical Research Council, Lehmann wrote

I had the satisfaction of seeing some 60 research workers from nearly all parts of the world, passing through this Unit... I think it might be considered particularly satisfactory that 5 of the Theses were produced by men from Ghana, Nigeria, Tanzania, Mexico and New Zealand... [with five remaining] from Venezuela, Saudi Arabia and Greece.

The haematologist J.V. Dacie wrote that many of these workers ‘became leading figures of haemoglobin research in their own countries’. Lehmann clearly considered this to be a significant part of his legacy. This cosmopolitan laboratory bolstered his credentials as a postcolonial ‘expert’, fostering global convivial bonds of friendship and collegiality, whilst also serving a narrative of scientific ‘development’.

Within a few years of the Unit’s establishment, it was clear that the MRC did not consider it to have a long term future. The 1967 progress report of the MRCAHU was circulated among various researchers in the field to assess the calibre of the Unit’s work. William Paton at Oxford described the results as ‘extremely interesting’ and recommended that the MRC should continue to support the Unit at its current

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134 Correspondence, Hermann Lehmann to Sir John Gray, TNA FD 9/1098.
size but that ‘enlargement may not be necessary… I think it has gained… by centring around Lehmann’s thinking and the link with Perutz’. He doubted that there could be a successor as ‘it is so much his own line… I suppose the haemoglobins will get exhausted’. In 1973, a MRC subcommittee visit to the Unit agreed that its work ‘was no longer as exciting as it had been when the Unit was initiated’. Officials concurred that, while his unit provided ‘very valuable clinical diagnosis and reference services’, Lehmann’s scientific staff ‘were not of the highest quality scientifically and they were not in a position to exploit fully the problems that their work had uncovered’. One commented that the Unit should be disbanded following Lehmann’s retirement as ‘since Lehmann had made this such a very personal field it might be difficult to see anyone with the ability to make a genuine research contribution stepping into his shoes’.

That it was such a personal field also suggests that few scientists were moving into Lehmann’s particular area of abnormal haemoglobin categorization because it had become a scientific cul-de-sac. In 1971, British haematologist Graham Serjeant, who had been undertaking clinical research into SCA in the Caribbean for five years, came to the MRCAHU with the intention of pursuing a PhD. Once he had arrived, he later wrote, ‘after the first three months sitting in a laboratory in Cambridge while the clinical studies in Jamaica had ceased, it became clear that this was the wrong decision’. The real work was back in Jamaica, undertaking further research into the clinical course of SCD, and for Serjeant the Cambridge laboratory setting felt too far from the action. After negotiations with the MRC about funding for his work in Jamaica, Serjeant returned to the University of the West Indies to begin the Jamaican Cohort Study of Sickle Cell Disease, which went on to follow 800 subjects over four decades. A year later, just as the MRC and Lehmann were disbanding the MRCAHU, Serjeant wrote to the MRC again to ask for funding for a project researching the effect of the alpha thalassaemia trait on patients with SS disease. A pilot study had already been done by sending blood samples

138 Ibid.
139 Letter, M. Moore to H. Bunje, ‘Visit of Professor Lehmann,’ 7 March 1974, TNA FD 9/1098.
from 50 ‘elderly’ Jamaican patients with SCD to Joe White at Hammersmith Hospital
in London for analysis through chain separation and radioactive counting –
techniques Serjeant learned in Lehmann’s laboratory. The haematologist Richard
Huntsman – a longtime friend and collaborator of Lehmann’s – was consulted for his
opinion about the project, and he responded that

There is no doubt about current intense interest in the factors that ameliorate
the clinical course of sickle cell anaemia. One of the factors, which warrants
further study, is the role of [alpha] thalassaemia, which is the subject of Dr.
Serjeant’s proposed project. There is no doubt about the scientific value of the
work or, for that matter, the availability of clinical genetic material in Jamaica.
There is no mention of staff and I therefore, imagine that either Dr. Serjeant or
his wife will be technically responsible for the tricky and somewhat tedious
method.\textsuperscript{141}

However he also queried why the project planned to end the collaboration with Joe
White and his blood analysis by conducting the analysis in the Caribbean rather than
shipping the samples to London. ‘[I]t is puzzling why the present and apparently
satisfactory working relationship with Dr. White is being terminated… just when
results are beginning to emerge’, he wrote, concluding that ‘[i]t is up to the MRC to
decide whether the envisaged scheme is likely to provide a more satisfactory
outcome than the present arrangements’.\textsuperscript{142} The MRC provided the Jamaican unit
with ‘generous and sustained funding’ for decades.\textsuperscript{143}

Huntsman was struggling to adjust to a shift in the dynamic between the field,
the clinic and the laboratory. Expressing his support for the project in negative terms
(‘there is no doubt’), he acknowledged ‘current intense interest’ in the clinical course
of SCA, and obliquely referenced ‘the availability of clinical genetic material in
Jamaica’. Accustomed to the UK’s dominance in terms of laboratory methods,
Huntsman was uncomfortable with the samples not making their way to London, and

\textsuperscript{141} Letter, R.G. Huntsman to A.M. Baker, 4 July 1973, TNA FD12/198.
\textsuperscript{142} Ibid.
\textsuperscript{143} Serjeant and Serjeant, ‘Jamaica and Research in Sickle Cell Disease’, 462.
skeptical that analysis using the ‘tricky and somewhat tedious method’ could be performed in Jamaica. One colleague advised Serjeant that the MRC would ask, ‘[d]oes anybody here have experience in the necessary techniques? It seems unlikely if previous analyses were forwarded to London’.\textsuperscript{144} Serjeant explained that he was trained in the technique as a result of his time ‘with Prof. Lehmann in Cambridge’, and that the reason specimens had been forwarded to London in the past was the ‘lack of appropriate equipment here’ rather than a lack of expertise.\textsuperscript{145} Huntsman’s reference to ‘the availability of clinical genetic material in Jamaica’ reveals his commitment to a different set of clinical questions – for though the research project was intended to explore both genetic molecular structure and the patients’ symptoms, Huntsman referred to SCA as completely abstracted from the bodies and people it affected. His phrasing also hints at the MRC’s rationale behind funding the Jamaica study – that SCA was a tropical, not a domestic, problem and so could only be researched in the tropics. Despite the migration of hundreds of thousands of Caribbean people to the UK in the preceding decades, the many samples sent to the MRCAHU from UK-based doctors, and Huntsman’s desire to defend the pre-eminence of the British laboratory, SCA could not be acknowledged as a problem requiring attention in Britain. Two years after Serjeant’s return to his MRC unit in Jamaica, Serbian haematologist Milica Brozovič took up a post at Central Middlesex Hospital in London, where she began to investigate the problem of SCD among the local patient population. When describing her research challenges she explained that

\begin{quote}
first of all we had to have people recognise [the issue]... One of our problems was that most of the [research into] medical care and medical problems came from the… MRC Sickle Cell Unit. And all their money for sickle cell disease, I never got one iota of money from MRC for sickle cell disease, not that I didn’t try.\textsuperscript{146}
\end{quote}

\begin{footnotes}
\textsuperscript{144} Letter, A Davis to Graham Serjeant, ‘Alpha Thalassaemia and SS Disease’, May 16 1973, TNA FD12/198.
\textsuperscript{146} Milica Brozovič, interview with Grace Redhead (henceforth GR), 22 October 2018.
\end{footnotes}
Individuals with SCD within post-war British hospitals continued to be invisible to the MRC, who located the research ‘field’ outside Britain.147

Conclusion

The MRCAHU was in operation during a shift in ‘(post)colonial medicine’ that Bivins has characterized as ‘expertise once defined by climate and place became defined instead by culture and race’ as a result of the influx of Commonwealth migration.148

As this chapter has shown, however, place continued to define expertise – whether it was the field research or local contacts of the practitioners of medical genetics, or the birthplaces and migration habits of their subjects. Genetic researchers struggled with the implications of Commonwealth migration and continued to reify population distributions that pre-dated decolonization. The perception of geographical access to ‘genetic material’, even when researching the symptoms of and treatments for SCD, was influential in determining the allocation of funding. This emphasis on overseas research, and the comparative neglect of the trait in British citizens and residents, constructed haemoglobin disorders as minority concerns for the British state.

This continued focus on ‘the field’ and prehistoric history is unsurprising given the evidence that the meaning of SCA in the 1950s and 1960s was constructed within a research community that was heavily influenced by colonial anthropology. Biochemists such as Lehmann encountered people like A.C. Haddon in their institutions and social circles, and their conversations could shape his research agendas. Lehmann could also draw on the scientific expertise of biochemists and haematologists such as Joseph Needham, Max Perutz and A.E. Mourant to be awarded a prestigious MRC unit. In this context, SCA sat neatly between the

147 It was comparatively unusual for the MRC to establish research units overseas – as a recent MRC blog explains, the MRC currently has only two units overseas (in The Gambia and Uganda) and ‘we haven’t made a habit of setting up units around the globe’. The article points to the MRC’s Epidemiological Research Unit in Jamaica as an exception that ‘intrigued’ the blog’s author. See Stacy-Ann Ashley, ‘A lasting legacy in Jamaica’, Insight Blog, Medical Research Council, accessed 7 April 2019, https://mrc.ukri.org/news/blog/a-lasting-legacy-in-jamaica/.
research agendas of anthropological investigations into ‘race’ and biochemical analysis of genetic and molecular structure.

SCA had the potential to deconstruct notions of concrete racial types, and later in his career Lehmann emphasized the huge variety of regions and people that could be affected by haemoglobin disorders. Population genetics came to be equated with scientific anti-racism, enabling a prevalent view that modern biology ‘can neither be racist nor sanction race-based discrimination’ because it proposed that ‘only populations and not races exist in the natural world’. The use of population genetics to debunk scientific racism is now common to discussions of racial theory in the humanities and social sciences. Colin Kidd, in his prologue to The Forging of Races, cites genetic characteristics such as Mourant’s research into the distribution of A/B/O blood groups, and Lehmann’s discovery that the sickle cell trait can be found in non-African groups to show that ‘race’ is a ‘bogus scientific category’. These studies paved the way for the use of the human genome in historical, archaeological and biomedical research today. The methods established by Lehmann, Mourant and others – which disavowed connections between ‘race’ and nation, culture, religion and ethnicity, but reserved ‘race’ as a category with value for medical research and population genetics – continues in the present. In a 2011 study of twenty-first-century genome-wide association studies (GWAS), Joan H. Fujimura and Ragan Rajagopalan concluded that genetic researchers ‘use notions of geography to define and interpret ancestry in their research designs and in the technologies used to denote populations’. Fujimura and Rajagopalan termed ‘this process of tracing genetics via ‘ancestry’ to geographic locations genome geography… deeply informed by scientific and socio-cultural discourses on human geography and human history, including theories of the origins and migrations of human groups’.


examining the history of medicine, such as Lisa Gannett, have found to the contrary that bio-geographic methods do not escape but rather build upon specific American and European social and political constructions of race.\textsuperscript{153} Beyond the field of genomics, the use of the human genome as a historical archive from which we might ‘objectively’ infer the origins of man, without cultural bias or social conceptions of ‘race’, is only increasing.\textsuperscript{154} The work of Lehmann and his colleagues on the distribution of SCA was the beginning of a practice that continues to endure in biological sciences, genetics, anthropology, and consumer technology. The commercialization of DNA ancestry tests based on population dataset analysis has enshrined DNA as influential in how individuals understand their own ancestry and identity.\textsuperscript{155} A case study of the MRCAHU, sited in the crossover between molecular biology and anthropology, demonstrates that the scientific knowledge required to extract information from the genome-archive is as self-consciously constructed as any colonial archive.

\textsuperscript{153} Gannett, ‘Biogeographic ancestry and race’, 176.
Chapter 2: From Whitehall to West Bromwich: Sickle cell policy and funding in central and local government, 1968-1993

On 5 August 1986, a twenty-seven-year-old man, Stephen Bogle, was taken ill in a chip shop in Hackney and exhibited ‘unusual behaviour’. A local shopkeeper, who knew Bogle, called an ambulance for him. When it arrived, Bogle refused to get into the ambulance and the crew in turn called the police. A police officer arrived and unsuccesssfully tried to persuade Bogle to get into the ambulance, and finally – thinking Bogle might be an absconded psychiatric patient, took him to Hackney Police Station. There, the officer telephoned several hospitals, none of which knew of Bogle, and looked him up in police records where he learned Bogle was subject to an outstanding arrest warrant, for minor driving charges and possession of ‘a small amount of cannabis’. He was then transferred to Thames Magistrates Court, where he was remanded in custody for a week. Finally, it was in the hospital wing at Brixton Prison where it was learned that Bogle had a history of sickle cell disease and mental illness. He was pronounced fit to attend court on 12 August, and – unable to stand – transported in a wheelchair to Thames Magistrates Court where he was laid on the floor of a court cell at 11am. His solicitor, worried about his condition, summoned his probation officer, who called a police surgeon, who rang for an ambulance. When the police surgeon returned, Bogle was not breathing. Efforts to resuscitate him failed. Bogle died shortly before 1pm.

The circumstances of Stephen Bogle’s death were subsequently criticized by the advocacy group and charity the Sickle Cell Society, who argued that the police had failed in their duty of care to Bogle at several points. Although he had come to the attention of police because of illness, he was not examined by a police surgeon and his condition was unknown when he was remanded in custody. Once his condition was known in Brixton Prison hospital wing, he was not rehydrated and by

1 Sickle Cell Society, ‘Note on inquest on Stephen Bogle (sickle cell patient) who died at Thames Magistrates Court on 12th August 1986’, 20 January 1987, Black Cultural Archives (BCA), RC/RF/17/02/C.
2 Letter, Douglas Hurd to David Steel, 13 April 1987, BCA RC/RF/17/02/C.
3 Sickle Cell Society, ‘Note on inquest on Stephen Bogle’, BCA RC/RF/17/02/C.
the time he was declared fit to appear in court he was very dehydrated – a life-threatening state for a sickle cell patient. He was not examined, and despite his known SCD, did not have a blood test before being transferred to the court.\(^4\) Several witnesses at the court testified that police officers had said that Bogle was ‘a malingerer’, not ‘co-operative’ and was in a wheelchair because he was ‘able but not willing to walk’. Bogle’s physical illness was instead pathologized as a resistance to police intervention and a reluctance to face justice.\(^5\)

Bogle’s case became the subject of correspondence between the Sickle Cell Society, the race equality think tank the Runnymede Trust, and the Home Secretary Douglas Hurd. Hurd was lobbied by Labour Party MPs including Reg Freeson, Renee Short and Bryan Gould, and Tory peer Baroness Lucy Faithfull. Labour MP Chris Smith raised the case in a written question to the Home Office in 1988, asking for a statement and a review of training and instructions for prison medical staff ‘on the diagnosis and treatment of sickle cell disease’.\(^6\) The chair of the Home Affairs Select Committee, Conservative MP John Wheeler, wrote to Scotland Yard’s Personnel and Training Commissioner, who responded ‘I have been advised… that the predominant symptom of the disease is pain, and that diagnosis can only be made after laboratory investigation’\(^7\).

Stephen Bogle’s death witnessed the interaction of two branches of the post-war British state – the police force and the health service. In the Hackney chip shop, he had been claimed by both an ambulance and a police car when he was first taken ill. Over the following days, he was evaluated by doctors and prison officers, who weighed up whether he was unwell or a ‘malingerer’, and was ultimately determined to be well enough to face a court. As the Sickle Cell Society observed, the crossroads between the caring and punishing arms of the state had opened up several times between 5 and 12 August 1986. His doctors failed to claim him as someone who needed their care, and left him in the hands of the criminal justice system. He died, not in a hospital bed, but in a court cell.

\(^4\) Letter, Elizabeth Anionwu to Douglas Hurd, 21 January 1987, BCA RC/RF/17/02/C.
\(^7\) Letter, M.J. Evans to John Wheeler MP, 13 March 1987, in Black Cultural Archive, RC/RF/17/02/C.
In 1999, Stuart Hall summarized the relationship between the British state and black communities in Britain, arguing that ‘black people have been the subject of racialized indifference, had their grievances largely ignored by the health service, and been subjected to racially-inflected practices of policing’. The relationship between Black British people and the state, as mediated by the police, has rightfully received much attention. Analyses of the police practice of ‘stop and search’, on deaths in custody and miscarriages of justice have illustrated the myriad ways in which Black British people were accorded a depleted form of citizenship, constructed as a social contagion, and ‘read’ by law enforcement as a threat in the post-war period. Scholarship has also turned to how the relationship between the state and its Black British subjects was mediated by the Welfare State, particularly the National Health Service. Jordanna Bailkin has shown that post-war welfare was shaped by imperial memory and the processes of decolonization.

Where Bailkin explores this through a series of social histories, Roberta Bivins and John Welshman have considered the relationships between postcolonial migration, ideas of health and disease, and the structures of the Welfare State, from the perspective of decision-making by government officials – in Whitehall and in local contexts, respectively. Kennetta Hammond Perry, in her examination of the architecture of state power and the death of David Oluwale in York in 1969, has illustrated the interplay between Welfare State indifference and the criminalization of Black Britons by the infrastructure of British police and courts. This chapter will

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10 Hall, ‘From Scarman to Stephen Lawrence’, 188.
examine how the Department of Health and Social Services (later the Department of Health), the Home Office and the Department of Environment dealt with the question of SCA. Their inaction left a vacuum which, as Chapter 3 will show, led to much confusion, misinformation and improvisation in hospital wards and GP surgeries. But this chapter will demonstrate that this vacuum was the product of much internal discussion, consensus and disagreement over the course of the three decades, and will explore the internal rationalizations that constituted this ‘racialized indifference’.

The British state has long been invested in the appearance of tolerance and the overt rejection of ‘racialism’. During World War Two, Colonial Office public relations officials scrambled to repair Britain’s reputation, counter the practices of ‘colour bars’ both in colonies and the metropole, and disguise the ideology of white supremacy that had long been the implicit justification for the British Empire. As Sonya Rose put it, the paradox was that ‘[b]eing British in Britain meant being white. It also meant being tolerant’.14 Under Harold Wilson’s first term as Prime Minister, a set of damage limitation policies focused on the control of immigration, legal steps to outlaw racial incitement, and the promotion of ‘integration’ through the introduction of race relations infrastructure. In the context of the decolonization of Africa underway in this period, it was hoped that such methods and the minimization of ‘racial tensions’ would impress Commonwealth and wider global opinion.15 Under the ‘race relations paradigm’, migrants and non-white British citizens were implicitly required to culturally assimilate to uphold their end of this deal, and failure to do so quietly disqualified them from the protections and provisions of the state.16 By the late 1970s, this relationship was slowly being reconfigured, with ‘racial disadvantage’ rising as a ‘political term of art’ within government, reflective of an increasingly pluralist attitude towards public services.17 Symptomatic of this was the 1976 Race Relations Act, which identified local authorities as responsible for promoting ‘equal

17 Bivins, Contagious Communities, 357.
opportunities’ between ethnic groups. The 1980-81 uprisings and the subsequent Scarman Report saw state institutions acknowledge notions of institutional racism – which had long been discussed in anti-racist and activist communities – for the first time. However, Scarman defined it as institutions ‘knowingly, as a matter of policy’ engaging in racist discrimination against minorities – which, as Stuart Hall argued and as many observed at the time, was blind to the character of the ‘very English kind of racism, which thrives, not against, but cozily inserted within, liberalism’. The Macpherson Inquiry into the murder of Stephen Lawrence in 1997 accepted that individual officials did not need to have racist intent for the institutions they served to implement racist policy. Jim Bulpitt, writing in 1986, described the British government’s approach to racial disadvantage and institutional racism as a strategy of ‘peripheralisation’, in which Westminster and Whitehall passed responsibility for ‘race problems’ to local government and local politics. In this way, successive governments were able to insulate the political centre from the toxic paradox of British identity in ‘one of the great political ‘jobs’ of the twentieth century’.

This chapter will show that these changing discourses on race and institutional racism, a shifting and reconfiguring understanding of the extent and nature of state responsibility for ethnic minorities, and a prioritization of avoiding the appearance of state racism (which resulted in central inaction and peripheralisation), shaped internal discussions and external policy on SCA. It will begin by analyzing the first substantive encounter, on record, between DHSS and SCA, as multiple MoHs began contacting the Department with urgent concerns about the possibly fatal interaction between anaesthesia and SCA in operating theatres, and finds that between 1968 and 1972 the Department – fearing the racialized condition was too toxic for a public pronouncement – sought to publish anonymous recommendations and unspoken screening. In the second section, this chapter will explore the Department’s first meaningful engagement with the question of screening and identification cards between 1974 and 1977, and find that officials were divided

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19 Hall, ‘From Scarman to Stephen Lawrence’, 194.
between those who feared the ‘eugenic’ resonances of such policies, and those who resented the ‘special treatment’ being accorded to ethnic minorities, as internal discussions erupted around what constituted racism. The third section will examine the fallout of the 1980-81 uprisings, with DHSS under pressure from other Whitehall departments, SCA became naturalized as a condition of the ‘inner city’ and the territory not of DHSS, but of the Department of Environment. In the fourth and final section, as voluntary organisations and sympathetic MPs petitioned the government for action, a new understanding emerged that racism was not drawing attention to difference, but failing to provide pluralist services for ethnic minority patients. However DHSS/DH continued to be slow and reluctant to act, failing to complete a flagship survey of SCA screening and with key spokespeople arguing that the condition had already received more than its fair share of resources.

A multitude of voices and opinions emerge from the DHSS (later DH) and the Department of Environment (DoE) archives. Sometimes there was broad consensus among officials (usually to delay action) and at other times they challenged or disagreed with one another, especially when action had been proposed. J.R. Hay observed that the structure and availability of state archives, and the tone of civil servant discussions, encourages the sense that ‘a serious and detailed study of their contents will reveal the vital and central processes of reform’, framing pressure groups as appellants whose requests and desires are granted or rejected depending on their accordance with the civil servants’ ‘interests, concerns and perceptions’.

Less clear, argued Hay, is the manner by which ‘issues were subjected to a form of selection, ordering and presentation which conditioned the views of civil servants’. This chapter will explore the role of shifting electoral politics, the changing understanding of ‘race relations’ and institutional racism, and advances in genetic technology, in influencing civil servant thinking on SCA.

The structure of state archives has inevitably shaped the argument of this chapter. Archives covering the period 1988-1993 have been made available through archival releases for the 2008-2015 Penrose Inquiry into the contaminated blood scandal, which in itself hints at the other conditions and policy areas that the civil

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servants in this report were dealing with. On the other hand, the state’s capacity to protect itself from archival releases has also shaped this report. Following Stephen Bogle’s death and an inquest attributing his death to ‘natural causes aggravated by a lack of care’, Douglas Hurd and other government officials deflected accountability to the pending outcome of an inquiry of the Complaints Investigation Bureau of the Metropolitan Police. Douglas Hurd observed in April 1987 that as the investigation was ongoing, he was ‘unable to comment at this stage on whether the correct procedures were followed or on whether improvements in procedures should be made as a result of this case’. In March 2018, I requested the report of this investigation in a Freedom of Information request to the Metropolitan Police Service. The MPS deemed the 400-page report exempt citing Section 38 (this file could damage an individual’s mental or physical health and safety), arguing that to release it would endanger the mental and physical health of any surviving friends and relatives of Stephen Bogle. This decision was subsequently upheld by the Information Commissioner’s Office. Jordanna Bailkin has observed that she found this exemption, and the application of Section 40 (the file contains sensitive personal information that an individual would not expect to become public) to be very common in the course of her research, while exemptions on the basis of Section 27 (information that might damage relations between Britain and another state) were comparatively infrequent. As Bailkin comments, the exemption of such ‘personal’ documents ‘may hide ways of seeing the state as well’. Such protections are likely to become more frequent with the introduction of the European Union’s General Data Protection Regulation (GDPR) in 2018. In Stephen Bogle’s case, in which a young man died due to medical negligence and for which the state deferred accountability until the conclusion of an investigation, this investigation itself and any answers it

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24 However, Bailkin is clear that her opinion is not that exemptions for personal information should be withdrawn. See Bailkin, The Afterlife of Empire, 13.
yielded are themselves protected from view in the name of health and safety – which, as this chapter will show, forms part of a consistent pattern in the self-justification of the state.

The anaesthesia panic, 1968-72

In January 1968, the Ministry of Health (which in November would merge with the Ministry for Social Security and become the Department of Health and Social Services, henceforth DHSS) encountered their first considerable policy challenge around SCA. Local Medical Officers of Health (MoHs) were deeply concerned about the risks of anaesthesia to individuals with the sickle cell trait or disease, and wanted advice on how this risk could be managed sensitively. For the next four years, the issue continued to resurface as DHSS officials sought advice from external experts, and discussed policy internally. These discussions reveal the anxiety that characterized discussion around SCA as the Department was pressed to issue advice. Discomfort with advising screening on a ‘racial’ basis and making commitments to pathologists’ workloads were policymakers’ primary reservations. Medical officers of DHSS, and local MoHs, saw the issue almost exclusively as one concerning children, reflecting an understanding of SCD as fatal before adulthood or as easing off after adolescence.

In December 1967, the Department of Science and Education (DSE) received an enquiry from the Croydon Medical Officer of Health and Principal School Medical Officer expressing concern about ‘supposed dangers from general anaesthesia to patients with sickle cell anaemia… apparently a problem related to non European immigrants’. The ‘dangers’ were that oxygen deprivation under anaesthesia could precipitate a sickle cell crisis even in an individual with the trait, leading to haemorrhage and sudden death. The Croydon officer wondered about the best way to test for SCA, and expressed that he was ‘reluctant to single out immigrants and still more anxious not to assume the burden of testing every child due to have a general anaesthetic’, adding that ‘[p]resumably it would be a problem of areas with

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large immigrant populations’ and enquiring if any other Principal School Medical Officers had raised the same concern.\textsuperscript{27} DSE passed the enquiry on to DHSS, and DHSS Medical Officer Pamela Aylett then wrote to anaesthetists around England, requesting further information about the risks of anaesthesia to those with SCA. Upon seeing Aylett’s information on the subject, an official from the Department of Education and Science suggested in January 1968 that ‘[i]n view of its general interest, would it not be worth having a note about this hazard in the new quarterly journal published by the Ministry of Health?’\textsuperscript{28} Aylett passed this suggestion on to her colleagues, noting that ‘[t]his type of disease is probably more common owing to immigration of Jamaicans to this country… Although it would not be surprising to get anoxia with nitrous oxide dental anaesthesia, people may not have equated this with a possible risk for coloured children’.\textsuperscript{29}

The Department took this risk seriously, and in February 1968 requested a memorandum of advice for anaesthesia in children with SCA from the anaesthetist Aileen Adams. DHSS requested that the resultant ‘useful’ memorandum be published in the \textit{British Medical Journal}, the \textit{Lancet}, ‘or possibly both’.\textsuperscript{30} However, they were stopped in their tracks by the reluctance of the experts to put their names to the opinion. Adams and her colleagues were reluctant to commit their names to their advice, agreeing on the condition that ‘you [DHSS] publish it as your guidance, based on information from your medical advisers… it is in a form we would not choose if we published it as a scientific article. It was couched in terms for the guidance of doctors and dentists who might encounter this problem’.\textsuperscript{31} Internal discussion by DHSS colleagues shows that many considered the problem urgent – ‘[w]e need to get advice to hospital anaesthetists, MOoH/P.S.M.O.s and all dentists’,\textsuperscript{32} one comment urged, while Deputy Chief Medical Officer Henry Yellowless commented that ‘[w]e really can’t wait for an indefinite period… to get something prepared on this’.\textsuperscript{33} Yet they were also reluctant to put their names to the

guidance, and so the topic lay dormant until May 1969, when Wolverhampton Borough Council Dental Services wrote to the DHSS Chief Dental Officer reporting that at a recent national meeting of dentists grave concern was expressed by Chief Dental Officers with large immigrant populations about the administration of anaesthesia to West Indian children. It is generally felt that most West Indian children are prone to sickle cell anaemia... When the disease is latent anoxia could precipitate sickling of the cells and where it is active anoxia could prove fatal. As children with the disease present no obvious signs or symptoms it is felt that blood tests are the only answer.\textsuperscript{34}

This letter reveals a great deal of misunderstanding around SCA, including the concept of ‘latent’ and ‘active’ disease, the idea that most West Indian children were ‘prone’ to the condition, as well those with the disease presenting ‘no obvious signs or symptoms’. This description of children of Caribbean origin reveals a perception of them as medically unpredictable, patients who despite all outward signs of health might suddenly die in the hands of doctors or dentists. Some doctors, when contacted for their advice by DHSS, retrospectively ascribed sudden deaths by black patients to undiagnosed SCD. DHSS had consulted another anaesthetist on the issue the previous year, Dr W.D.A. Smith, who recalled that when he was training in anaesthesiology in Jamaica many years before he had ‘lost a young Jamaican following a spinal fusion. He regained consciousness, lapsed into coma, and at p.m. 48 hours later was found to have had acute sickling’. At the time, Smith had suggested that there might have been a period of anoxia while he was intubating the patient, ‘but looking back upon the incident through the mists of time it would not surprise me if blood replacement was inadequate’.\textsuperscript{35}

A month later, the Medical Officer of Health for West Bromwich, Dr Bryant, also wrote with the same enquiry to DHSS, explaining that he had received similar

\textsuperscript{34} Letter, S. Awath-Behari to DHSS Chief Dental Officer, 7 May 1969, TNA MH160/601.
\textsuperscript{35} Letter, W.D.A. Smith to Pamela Aylett, 10 April 1968, TNA MH160/601.
queries from school services.36 ‘We are anxious to determine whether or not it is necessary to go to this amount of trouble,’ Dr Bryant explained, ‘which involves considerable work for the Pathological Laboratories, [to screen] all patients of this particular stock who present themselves for anaesthesia.’37 Testing every patient ‘of this particular stock’, Dr Bryant implied, would be punitive for the workload of hospital pathologists. Within this question from the MoH was an unspoken financial calculation around ‘going to this amount of trouble’ for the ‘immigrant’ patients of a ‘particular stock’. Dr F Riley, Senior Medical Officer at DHSS, forwarded Bryant’s enquiry to the paediatrician Hugh Jolly, expressing anxieties about screening people based on their race. ‘I would have thought that decisions regarding investigation should be made on an individual basis, rather than being applied to a racial group’, Riley commented.38 Jolly replied that though he agreed ‘in general’ with the decision to investigate being made on an individual basis, ‘this is an occasion when investigations must be based on a racial rather than an individual basis. It is essential that every child of negro stock should have sickle cell anaemia disease excluded before anaesthesia because of the possible risks to them of anoxia’.39 Jolly’s advice therefore focused on prioritising patient safety over the possible optics of screening individuals based on their origin, although it was acknowledged that it was undesirable to do so. Although it was not discussed explicitly, it seems clear that both felt that screening ‘on a racial basis’ had eugenic overtones – even as they used the typological terminology of racial science such as ‘of negro stock’ in their discussions. The language of ‘stock’ had been particularly prevalent in objections to migration from the Caribbean during the 1950s.40 In these exchanges, reluctance to ‘[go] to this amount of trouble’ for patients ‘of this particular stock’, and distaste around ‘[applying genetic tests] to a racial group’ and the possible eugenic implications of such, were aligned.

36 This flurry of attention to this particular issue may have been stimulated by a paper in the British Journal of Anaesthetics a few years earlier, a copy of which is in TNA MH160/601. A. A. Gilbertson, ‘Anaesthesia in West African patients with sickle-cell anaemia, haemoglobin SC disease, and sickle-cell trait,’ British Journal of Anaesthetics 37, 8 (1965): 614-22.
37 Letter, H.O.M. Bryant to Dulyn Thomas, 13 June 1969, TNA MH160/601.
40 Schaffer, Racial Science and British Society, 162.
For both or either of these reasons, DHSS was reluctant to consider the broader implications of the sickle cell trait, beyond knee-jerk reactions to enquiries from regional MoHs. That October, DHSS received another enquiry, this time from the Coventry MoH, one Dr Clayton. He explained that the subject of SCA and anaesthesia ‘has been exercising our thoughts here quite acutely, in order that necessary action can be taken to ensure the utmost safety for those at risk’. He also inquired about the Department’s future thinking on screening for the condition, pointing out that ‘the sickle-cell trait is liable to become of much wider implication since, presumably, it can be passed on to succeeding generations of children who may not be entirely of negroid stock.’ Clayton’s implication was that relationships between white and Caribbean or African people might mean that a screening practice focused on racial groups would have a time limit, hinting at the problems in focusing solely on black communities. But in response, DHSS official Dr Dulyn Thomas simply repeated the recommendation that ‘investigations must be made on a racial, rather than an individual basis’. Even in internal memos, Clayton’s suggestion was not discussed. For DHSS, policymaking on SCA would continue to be limited to black children and their encounters with anaesthesia. By this point, Hermann Lehmann – who had shown two decades earlier that SCD was not limited to Africans but also found in parts of South Asia – had been in receipt of an MRC grant for three years, with which he was cataloguing haemoglobin variants across the world (see Chapter 1). Lehmann had responded to Pamela Aylett’s initial enquiry about anoxia and SCA in 1968, cautioning that possibly the impact of the arrival of the disease in this country might have to be considered from a wider aspect than merely that of dental anaesthesia… I notice that there is still a great deal of ignorance on sickle cell anaemia in this country, which is not surprising because it is a completely new factor which

most medical men have not been confronted with during the time of their training.\textsuperscript{43}

Though he did not explain further, Lehmann’s suggestion was that a more important concern might be increasing numbers of people with sickle cell disease itself, or the wider education of British healthcare professionals on the signs and symptoms of the disease, given their ‘ignorance’. Lehmann’s suggestion was ignored, it seems, as no response to his letter is on record, and broader policy to diagnose or treat the condition was not discussed.

This flurry of queries from regional Medical Officers of Health in 1969 meant that by December, DHSS had revived the idea of publishing Aileen Adams’s memorandum – but both Adams and DHSS itself were still unwilling to put their names to it, for fear of accusations of interference by pathologists, or of racism. In October, one DHSS staffer complained that ‘[p]ublication of the paper… would have relieved us of the embarrassment of issuing clinical advice’.\textsuperscript{44} In a letter to the \textit{British Dental Journal}, DHSS official W Holgate wrote

\begin{quote}
[a]s yet we do not appear to have had any fatalities as a result of dental activities on susceptible children, but you may think it would be a good thing for the profession to be made aware that theoretically, at any rate, adverse reactions could occur… At present, none of [the experts] are prepared to commit themselves, and this makes it difficult for the Department to make any official pronouncement.\textsuperscript{45}
\end{quote}

Without medical backing, DHSS was slow to respond to the local MoHs who were increasingly frustrated with the absence of guidance. Hassled by Dr Bryant of West Bromwich for an answer, DHSS took almost a month to respond, explaining that there were ‘still some problems which have to be resolved on this subject since it concerns the available laboratory and other hospital services’. In the meantime,

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\textsuperscript{43} Letter, Hermann Lehmann to Pamela Aylett, 29 April 1968, TNA MH160/601. \\
\textsuperscript{44} Letter, J.G. Thomson to Delyn Thomas and C.G. Siegruhn, 16 September 1969, TNA MH160/601. \\
\textsuperscript{45} Letter, W. Holgate to J.A. Donaldson, 5 December 1969, TNA MH160/601.
\end{flushright}
DHSS had arrived at a compromise which required as little testing – and therefore as few implications for eugenics or pathologists’ workloads – as possible. They advised that ‘[w]here possible, dental surgery in patients of African and West Indian descent should be carried out under local analgesia… Where general anaesthesia is required, laboratory investigation must be carried out’, and adding that the case for routine screening ‘is a difficult one and still under consideration’. Privately, DHSS officials admitted among themselves that they had not answered Bryant’s questions. ‘[W]e have not the answers to these problems & that Dr Bryant must sort out locally, presumably with SAMOs aid, & in consultation with the hospitals’ pathologists’, one senior official noted.

In December 1969, Aileen Adams’s unpublished memorandum was circulated to Regional Senior Medical Officers in December 1969 by DHSS official J.D. Laycock. DHSS finally published Adams’s memorandum under ‘expert contributors’ in the *British Medical Journal* in April 1970. Adams had revised her recommendations, ‘having spent another period of time in West Africa’. She did not explain what happened during her trip that changed her mind, but this experience had convinced her that her previous recommendations were ‘perhaps unnecessarily cautious’. Adams suggested instead that short procedures under general anaesthetic could be possible if the patient received oxygen before and after the operation and ‘at an inhaled oxygen concentration of 30% during the procedure’.

Martin Moore has noted that the British medical press in the 1950s and 1960s were fascinated with ‘tropical’ variants of known chronic diseases such as diabetes, and much funding was available in these decades to research exploring ‘common chronic diseases in populations deemed socially and biologically different to those ‘at home’.” In this example, connections forged by colonial medicine enabled British doctors to test treatments on populations in ‘Africa’ deemed biologically similar to black British people. This expertise enabled Adams to revise her advice and further relieve any

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46 Letter, ‘Sickle Cell Anaemia’, Dr Duly Thomas to Dr H.O.M. Bryant, 3 October 1969, TNA MH160/601.
47 Memo, Dr Laycock to Dr Thomas, 2 October 1969, TNA MH160/601.
48 Letter, ‘Sickle-cell diseases in relation to anaesthesia in school clinics’, J.D. Laycock to Dr Shaw, Dr Fleming, Dr Burbridge, Dr Lees, Dr Riley and Dr Dennis, 11th December 1969, TNA MH160/601.
pressure on the pathological services, since it meant that the patient would not need to be screened even when general anaesthesia was necessary. Although it was not mentioned in correspondence, this may explain why this iteration – and not those which made recommendations to pathology departments – saw the light of publication.

A sense of anxiety and bewilderment emerges from these discussions between DHSS, MoHs and clinicians, which centred on the image of ‘immigrant children’ as posing an unknown quantity in the school dental chair. The sickle cell trait – poorly understood and defined – was understood as lurking invisibly within these children, concealed partially (according to Adams’s memorandum) by their ‘dark skin’ which would not show the ‘pallor’ that was the warning sign of anoxia while under anaesthetic. The emphasis on expertise and experience from Africa suggests that DHSS felt the inexperience of white British doctors and dentists might prevent doctors from perceiving illness in these children. Despite their reluctance to act, the urgency of many of these communications suggests that DHSS did understand the welfare and safety of these children to be their responsibility, and feared a scandal resulting from the possible deaths of children after anaesthesia. However, their action was weighed against the financial and political cost of committing pathologists across the country to testing every black child’s blood, an idea that every DHSS officer refused to entertain. The various officials tasked with resolving this problem chose to sidestep it, neither implementing small-scale screening nor considering the broader implications of SCA. Officials focused on the risk of individuals dying during an operation, but not on the diagnosis and treatment of individuals with SCD.

Moreover, given the Department’s concern about the possibility of fatalities as a result of the interaction between sickle cell and anaesthesia, when news of a fatality did come in 1972 officials were remarkably sanguine. On 12 September 1972, a nineteen-year-old woman named Joyce Bogle died after a routine termination of pregnancy in a clinic in West London. Hammersmith Hospital had refused to perform the procedure because she had the sickle cell trait, so instead she attended the London Pregnancy Advisory Service who made an appointment for her in a West London clinic. Neither conducted a sickling test, and Bogle did not
inform them that she had the trait, but Dr Maylor, the anaesthetist, said she had followed the recommendations of the 1970 BMJ publication placed anonymously by DHSS and Aileen Adams. Shortly after the operation, Maylor was called to the ward ‘where she found Miss Bogle to be dead’. Post mortem revealed sickling in major organs and the coroner recorded the cause as ‘Medical Misadventure’, accepting ‘the assurance of the nursing home… that in future the routine of admission would be amended to include sickle cell test’. 51 Unofficial DHSS policy had been followed, a death had occurred, and the coroner had determined that screening was essential – and yet DHSS were unruffled. A DHSS official attended and sent a report to the Department. One official asked ‘whether attention needed to be drawn again to this type of disaster’. 52 Considering the Department’s previous fear for such ‘fatalities’, their concern was muted. ‘The problem of sickle cell anaemia in relation to anaesthesia was raised at a meeting of SAMO’s in Sept 1970’, Laycock responded. Another suggested that ‘[i]n view of the way this has been ventilated recently, I am inclined to think that a further approach is not necessary’. 53 Laycock summarized the position to his colleagues that despite the recent death ‘of a woman of 19… it was decided that the hazards of sickle cell disease in relation to anaesthesia were already sufficiently known not to require further publicity’. 54

This indifference to Joyce Bogle’s death highlights the focus of the anaesthetic panic – not adults, but children. Adults carrying the sickle cell trait were almost absent from the policy discussions at DHSS and from the letters of concern from doctors across England, but their children were a subject of anxiety. In their study of Birmingham Education Authority, Christian Ydesen and Kevin Myers have argued that immigrant children were a focus of the ‘imperial welfare state’ and that school attendance was seen as a mechanism by which ‘assimilation’ could be engineered. Some teachers advocated medical regulation, with complaints in 1967 that ‘in general immigrants are keen to have their children go to school but evasive about sending them to the doctor’, and some schools implemented pre-term medical

51 Letter, Richard Trussell to Admiral Holford and Dr Beddard, December 1972, TNA MH160/601.
52 Internal memorandum (64), F.D. Beddard to Dr Shaw, 4 January 1973, TNA MH160/601.
53 Internal memorandum (67), Richard Trussell to J.D. Laycock, 2 February 1973, TNA MH160/601.
54 Letter, J.D. Laycock to Dr Maycock and Dr Wilson, 19 June 1973, TNA MH160/601.
inspections.\textsuperscript{55} Olivier Esteves has shown that such policies reflected ‘[s]tate simplifications and bureaucratic preconceptions’ within 1960s Whitehall, which identified ‘immigrant children’ (as they were often called) as a public policy problem.\textsuperscript{56} West Indian children were also the subject of state concern due to the influence of ‘Bowlbyism’ on social science research, which pathologized West Indian mothers as ‘curiously cold and unmotherly’ and inadequate for child development.\textsuperscript{57} Such assumptions about Black Britons as parents, and the focus on African and Caribbean children, form part of the longer history of the infantilization of black people by liberal imperialism.\textsuperscript{58} It may, therefore, not be a coincidence that this muted response was to the death of an adult from anaesthetic-induced sickling following the termination of a pregnancy by a woman of Caribbean descent. This focus on children also reveals the extent to which DHSS policy was based on reports from colonial doctors, who had initially understood SCD to be a disease of childhood.

Later in the 1970s, officials frequently justified their reluctance to act on the basis of the failure of United States Sickle Cell Anaemia Control Act in 1972.\textsuperscript{59} This Act authorized one hundred million dollars for screening at a local level, but the provisions of state laws meant that its implementation was highly varied. Nine states insisted that couples could not receive marriage licenses without being tested, with two states specifically targeting black couples. Only one state kept the results confidential. Black communities responded with anger and alarm to state coercion, and the programme became marked by controversy.\textsuperscript{60} However, this section has shown that DHSS reluctance to act predated the mistakes made in the United States, and reveals that British policymakers were already hesitant to take steps on the issue – whether because of the fear of the shadow of eugenics, pressure on pathology services, or a sense that ‘immigrant children’ were too much trouble to take such drastic and costly steps for.

\textsuperscript{58} Frantz Fanon, Black Skin White Masks (London: Pluto Press, 2008 reissue): 19.
\textsuperscript{59} Bivins, Contagious Communities, 335.
\textsuperscript{60} Cowan, Heredity and Hope, 164-6.
Though the previous section showed that DHSS were reluctant to consider the broader implications of SCA, including diagnosis, treatment, and the ramifications of a growing biracial population that might complicate unspoken, race-based screening, by the mid-1970s DHSS was engaging in both internal and external discussions about screening programmes for SCA. This section will show that anxieties about the sensitivity of the issue, implications of eugenics, and possible ‘sinister motives’ from the state, continued to mark the discussions of the issue behind the scenes. Moreover, an absence of pressure upon DHSS to act meant that many officials preferred to maintain the status quo. By 1974 representations from medical researchers such as David Weatherall and Hermann Lehmann had induced the MRC to hold an ‘ad hoc’ meeting on haemoglobinopathies and sickle cell disease. To the historian’s eye, this meeting reveals complacency among the attendees about the present state of the services for SCA, explicit anxiety about the political implications of ‘singl[ing] out’ one racial group, and a tendency to compromise by ‘encouraging’ local actions.

The meeting brought together clinicians, such as Dr Eric Stroud, a haematologist in South London soon to be closely linked with the Organisation for Sickle Cell Anaemia Research (OSCAR), and scientists such as Hermann Lehmann, as well as Gillian Ford who represented DHSS. The minutes began with a discussion of a paper on ‘Management of sickle-cell disease’ submitted to the group by the haematologist Dr John Stuart. Dr Gillian Ford, representing DHSS, commented at the outset of the meeting that ‘the department would be interested in screening and genetic counselling aspects, but had not yet initiated any activity in the field’. Newborn screening was not considered necessary, as there was ‘general agreement by the members that the initial identification of the disease did not appear to be a problem’, although Eric Stroud had outlined the risks of infection in childhood and the benefits of early diagnosis. The clinicians and policymakers at this meeting felt confident about diagnosis rates, and the ameliorative effect of Britain’s healthcare
service on the condition. During a discussion about a possible study on the ‘natural history of sickle-cell patients’ and the disease’s typical progression, John Stuart commented that a true picture would be impossible to gain, because ‘due to “therapy”, particularly with the use of antibiotics, the disease no longer exists in its “natural” state’. This optimism about diagnosis and penicillin prescription rates was later revealed to be very complacent by a 1981 survey by L.R. Davis, E.R. Huehns and J.M. White (present at this meeting), which found that the prescription of prophylactic penicillin in individuals with SCD was only 24% across the country, and that 44% of deaths were in children. Anecdotal evidence also suggests that many children and adults with SCD in this period died undiagnosed, and were only diagnosed at post-mortem. This suggests a great overestimation of the quality of care being delivered in British hospitals. Where challenges such as clinical follow-up were acknowledged, attendees blamed them on the at-risk population. The minutes recorded that ‘[t]he special problems of follow-up among the black community were discussed and it was agreed that there was important sensitivity to anything carrying implications that one race was being singled out for special attention’. The term ‘special’ here holds a triple meaning – used to signify what they saw as the cultural specificity of black communities, to reference sensitivity to any eugenic overtones of targeting a single group for genetic screening, but also suggestive of ‘special treatment’ for black communities that might elicit hostility from the white British population.

Attendees at the meeting proposed that efficacy of screening for SCD could be researched by selecting ‘four or five cities in this country’ where screening could be piggybacked onto the existing phenylketonuria screening programme, and the crucial ‘follow-up’ that such studies required could be achieved by ‘enlisting the aid of the existing health visitor network’. Gillian Ford summarised the discussion on

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63 One interviewee disclosed that her husband’s sister had died, aged 2, from undiagnosed SCD in Britain in 1970. See chapter 5.
64 Meeting minutes, ‘Ad hoc meeting on haemoglobinopathies and sickle-cell disease, 8 July 1974’, TNA FD23/1656, 3.
screening at the meeting to DHSS colleagues in a subsequent letter. Representatives had agreed, she reported, that ‘were screening to be carried out for sickle-cell or thalassaemia disease, the PKU specimen at 6 days old could be used rather than cord blood’. The national neonatal screening programme for PKU had commenced in 1969 and so the meeting acknowledged – less than five years later – that the technology existed for haemoglobinopathies to be nationally screened, with comparatively little expense. However, Ford noted that ‘general feeling of the meeting was that the time was not ripe for any national policy on screening at birth since the benefits which can be offered are marginal’. This was partly due to an acceptance among many that the severity of the disease would ensure early detection – and a sense that an early death of the condition was inevitable. However, despite their scepticism about a national policy on screening, the meeting agreed that pilot studies should be conducted and coordinated. Of those who were present, Linda Bellingham, Jillian R Mann, Charles Eric Stroud, John Stuart and David Weatherall conducted such haemoglobinopathy screening trials in newborns in their local institutions (as discussed more extensively in Chapter 3) between 1973 and 1988.

Discussion around the possible implementation of haemoglobinopathy cards for individuals with the disease or trait to present to their doctor or nurse also arose during the 1970s. The 1974 ad hoc meeting had not been enthusiastic about their introduction, and in 1975 DHSS official Dr Lewis wrote to one of the Department's

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66 Letter, Dr Gillian Ford to Dr Beddard, ‘Hereditary haemoglobinopathies (in particular sickle-cell anaemia and thalassaemia)’, 19 July 1974, TNA BN13/41.
advisers, Sheila Waiter, on the subject, explaining that several experts had ‘not favour[ed] the use of identification’. Scotland’s Health Services Scientific Council had expressed frustration at this decision, although had not submitted any evidence. ‘[I]f pressure from similar bodies or workers in the field continues’, Lewis wrote, ‘any expert group concerned might feel obliged to consider this matter’.72 Waiter was hesitant, arguing that

I have reservations about offering cards although there are advantages in having such information available in the event of an accident or other emergency. However there would be difficulties if you ask certain racial groups to carry an identification card which apparently sets the carrier even further apart from the majority of the population.73

Waiter feared the result of the state drawing attention to an existing divide, implying that the carriers are already ‘set… apart’ from ‘the majority of the population’, and that the card would only further identify ‘certain racial groups’ as other. Officials worried that to draw attention to SCD would be to identify these groups as biologically set apart, though identification cards may have helped patients to navigate encounters with medical staff. Identification cards had been made available to patients with haemophilia since the establishment of specialised haemophilia centres in the mid-1950s.74 Discussion was then again postponed until September 1976, when Dr Alan Smithies explained that ‘[m]y recollection is, although it is not in the note of the meeting, that an identity card was considered a sensible & useful measure but that it would be dependent on the Minister of State’s opinion’.75

Prevailing opinion from other DHSS officials was that ‘[u]nless we are under a lot of pressure of which I am not aware I do not think we should have an official card on the grounds of possible racial complication’.76 As one succinct note put it, ‘I am not aware of any pressures, on my side – “sleeping dogs”’?77 The officials at DHSS

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72 Memo, Dr Lewis to Dr Sheila Waiter, 26 February 1975, TNA MH160/601.
73 Memo, Dr Sheila Waiter to Mr Woolacombe-Adams, 8 September 1975, TNA MH160/601.
75 Memo, Dr Alan Smithies to Dr Pincherle, 4 October 1976, TNA MH160/601.
76 Memo, Dr Pincherle to Dr Draper, 4 October 1976, TNA MH160/601.
77 Memo, Dr Draper to Dr Pincherle, 6 October 1976, TNA MH160/601.
made it clear that without significant pressure from either above – the Minister of State – or below, from doctors and the communities in question, they would not take the initiative. The Department would not issue identification cards for another decade.

Efforts to push the Department’s policies forward were met with criticism from within. In June 1976, DHSS official C.G. Siegruhn circulated a draft memorandum on possible haemoglobinopathy screening to his colleagues, which he proposed would be circulated to General Practitioners to inform them about the haemoglobinopathies. The memorandum prompted a flurry of critiques from his DHSS colleagues which illustrate the different strands of opinions that deadlocked over the issue of SCA. Firstly, an anxiety that drawing attention to SCA in the black community would incite a racial self-hatred in individuals; secondly, anxiety that action on SCA would draw accusations of racism and the eugenic ‘optics’ of a state screening programme; thirdly, reflexive (if subtle) criticisms of the racist attitudes of colleagues; and finally, challenges over why SCA should receive such attention over other genetic conditions. Siegruhn began by explaining the conditions and their inheritance – including that sickle haemoglobin ‘is found also in the Mediterranean area, the Middle East and in the Indian subcontinent’, but continued (as did all DHSS policy discussions) to focus otherwise on the affected West Indian and African population in Britain.78 He made the argument that any screening and counselling programme would have to be predicated on a ‘satisfactory level of education in these population groups’, who needed to be informed ‘about the medical, social and economic implications of these disease, and to allay any fears that they are “unhealthy” people’. Siegruhn suggested in the memorandum that antenatal and newborn screening might prove simple, feasible and beneficial:

It would not prove difficult for hospital laboratories to screen the blood of babies at birth of known high risk groups for sickle cell disease, and then we would be aware of those who have the disease before symptoms develop... If

78 Memo, Dr C.G. Siegruhn to Dr Ford, Dr Waiter, Dr Mayall, Mr Draper, Dr Pincherle, Dr Wilson, Dr Radcliffe, Dr Rothbam, Dr Carr, Dr Ring and Mr Gibb, 2 June 1976, ‘Haemoglobinopathies – Draft Memorandum’, TNA MH160/601, 1(a).
a pregnant woman is found to have sickle cell trait or thalassaemia trait, it might be advisable to examine the blood of the husband as well.\textsuperscript{79}

Ford countered that it should be made clear that ‘the information obtained is for the benefit of the patient rather than any more sinister purpose – it would be better to avoid the expression “we would be aware”.\textsuperscript{80} Her comments anticipated that a screening programme would raise suspicions about malign surveillance or discrimination in gathering such genetic information. Siegruhn emphasised the ‘implications’ of the disease in his criteria for education, and implied that in the event of prenatal screening, if a couple with an affected foetus came to ‘the choice of having the pregnancy terminated’, he had a preferred outcome – although he also caveated that ‘[m]any couples may find a one in four chance of an affected child an acceptable risk and the decision must be theirs’.\textsuperscript{81} This caveat was not enough for Dr Doreen Rothman, a Senior Medical Officer at DHSS, who criticised Siegruhn’s implication that termination of pregnancies would be the preferable outcome of antenatal diagnosis. She emphasized the principle of ‘informed choice’, and argued that ‘the present wording is based on a eugenic approach which we have so far purposely avoided’.\textsuperscript{82} While this is one of the only uses of the term ‘eugenic’ in DHSS discussions on SCA, Rothman clearly argues that the shadow of eugenics has influenced Department discussion.

Moreover, both Rothman and Ford critiqued Siegruhn’s use of the term ‘immigrant’ to refer to at-risk groups. Rothman argued that the term was ‘misleading and may also be interpreted as offensive’, because it identified non-white people as migrant outsiders and white people as non-migrant insiders. ‘[A]ll immigrants are not at high risk of having abnormal haemoglobin – what about the Irish?’ she observed.\textsuperscript{83} ‘Immigrant’ had long been used as a synonym for black and Asian people in DHSS documents, and these letters between Siegruhn and Rothman indicate DHSS

\textsuperscript{80} Letter, Dr Gillian Ford to Dr Siegruhn, 16 June 1976, TNA MH160/601.
\textsuperscript{81} Memo, Dr C.G. Siegruhn to Dr Ford et al, 2 June 1976, ‘Haemoglobinopathies – Draft Memorandum’, TNA MH160/601, 10.
\textsuperscript{82} Letter, Doreen Rothman to Dr Siegruhn, 28 June 1976, TNA MH160/601.
\textsuperscript{83} Letter, Doreen Rothman to Dr Siegruhn, 28 June 1976, TNA MH160/601.
officials discussing what constitutes racism within the British state. Siegruhn, when defending the vagueness of the documents when it came to clinical management, admitted that writing the memorandum had required navigating the delicate nature of the subject, saying he had been concerned that 'the document will easily be available to individuals or pressure groups could use it in a very destructive way eg say that it discriminated against coloured immigrants'. Here Siegruhn suggested that accusations of racism or discrimination against the state were ‘destructive’, displacing fault for any slowness or vagueness in the Department’s response directly onto anti-racist critique. While Siegruhn received pushback along the lines of anti-racialism, and advice modifying the state’s expectations of any genetic counselling programmes, his underlying assumption that sickle cell needed a specific programme of action was also criticised. DHSS official JG Handby, of the HS2B unit, responded that his team were ‘looking generally at genetic counselling and related services at the present time with a view to issuing guidance to authorities about the development of services. In the light of this I have reservations about advising authorities on one particular group of conditions in isolation’. Handby and other colleagues also raised concerns about the cost of such a programme, and Siegruhn insisted in his defences that patient numbers were small, testing was already routine in some areas, and ‘[t]he severity of the disease however is such that it could be life threatening’, he continued, ‘and therefore prevention and identification of people at risk is a task no one can justify not doing’. Coming from the other side, Rothman also agreed that there was little need for a public pronouncement from DHSS, given the ‘many sources of published information’ available to GPs. There was no further discussion of the memorandum, and it does not appear to have been circulated.

The discussion over Siegruhn’s attempt at action illustrates that very different reservations about action on SCA – ranging from anxieties about state racism to pushback against ‘special treatment’ for ethnic minorities – had the same desired outcome: inertia. In the resulting vacuum, individuals and organisations on the ground and in the peripheries took responsibility on instead. These discussions also

provide an insight into differing discussions about policymakers’ definitions of racism. They perceived racism to be the discussion or promotion of biological difference, and had a horror of any state action reminiscent of ‘eugenic’ action, such as non-directive counselling, or discussion of a genetic condition predominant in certain ethnic groups. However, they did not observe that withholding care from an ethnic group, for whatever reason, could also constitute state racism.

‘Inner City Blues’: Local government and sickle cell under Thatcher

From the earliest days of ‘New Commonwealth’ migration, the ‘state’ response involved a combination of central government, local authorities and voluntary agencies. In the 1950s, special officers were appointed by local authorities in areas with migrant influx, and charged with assisting migrants with work and accommodation. In the 1960s, voluntary committees made up of representatives from social services, migrant organizations and other interested groups including trade unions, became formalized as Community Relations Councils.87 This chapter has established why DHSS was reluctant to act on and make policy for SCA. Arguments were consistently made for individual health authorities, medical officers of health and hospitals to make policy on a local level instead. This section will explore how government ‘urban’ funding dating back to the first Wilson government intended to target social problems in areas with high immigration were, under Thatcher, repurposed to provide money for health services. Jenny Bourne has argued that, under Thatcher, this money was made available with the hope that ethnic minorities would ‘police their own’.88 This section makes clear that they were expected to care for their own too. Through this outsourcing, DHSS and DoE created an environment in which SCA could be characterized as a biological disadvantage innate to black people, and separate from their social and economic position in British society. An exploration of the conflict and consensus between central and

local government over the allocation of resources to SCA reveals that the condition was perceived as a natural fit for ‘inner city’ initiatives administered by local authorities. Unlike other diseases historically associated with urban life, such as cholera, typhus and sexually transmitted infections, SCA is not infectious but hereditary, and so its positioning as a health concern of the ‘inner city’, tied to the profile of immigrants and ‘ghettoes’ reflects broader assumptions about black people, ‘race’ and geography in post-war Britain.

Government action on the ‘inner city’ was linked to a broad policy plan to tackle the ‘problem’ of immigration during the 1960s. In 1968, Labour Prime Minister Harold Wilson proposed an ‘urban programme’ in a speech on race relations in Birmingham. Formulated in the wake of Enoch Powell’s divisive ‘rivers of blood’ speech, it would target ‘areas of general social need’. Wilson framed the programme as channeling national and local government money directly to community groups, with projects operating within the limits set by their funders.89 The Urban Programme was implemented later that year, and extended by the 1969 Local Government Act (Social Need) to last until 1976, with an initial budget of £55 million.90 The funding process began with proposals from local groups which would be submitted to councils, who vetted the projects and then submitted a shortlist to the Home Office. Though immigrant areas were evidently the target of the Urban Programme – one of the initial criteria for determining areas in need of social support was whether more than 6 per cent of school places were held by immigrant children – the government tried to deny this. In 1968, Home Secretary James Callaghan insisted the government’s scheme was ‘colour-blind’. Otto Saumarez Smith suggests that the government feared any overt attempt to help immigrant communities would lead to resentment in the white British population, and so the ‘inner city’ became a shorthand, ‘semi-covert way to address issues of new immigrant communities’.91 The proposed bill for the Urban Programme was indeed met with alarm in the House of Lords, and some speakers worried that ‘coloured’ migrants were being accorded

89 Wild, ‘Black was the colour of our fight’, 164.
90 Ibid, 169-70.
'special treatment'. Other funding streams, such as Section 11 of the 1966 Local Government Act, permitted grants to be paid for expenditure on staff ‘in areas of immigrant settlement’. Despite these measures, by the late 1970s there was a widespread perception that the urban centres of Britain were in demographic and economic crisis. Deindustrialization and suburbanization had seen the exodus of jobs and capital from British cities. In response, with responsibility for the Urban Programme transferred from the Home Office to the Department of Environment, its minister Peter Shore announced the creation of the Inner City Partnerships Programme.

In May 1979, Margaret Thatcher entered Downing Street. Her concern for the ‘extra dimension of difficulty’ faced by ethnic minorities was minimal: when she touched on immigration during her election campaign, it was to make statements that ‘people are really rather afraid that this country might be rather swamped with immigrants with a different culture’. But she changed tack, Jenny Bourne argues, after the riots from April to July 1981 which swept across 26 cities in Britain. The budget of the Urban Programme was increased to £270 million for 1982/83, and 200 new ‘ethnic projects’ were approved. This new interest almost coincided with the entrance of SCA into the picture as a concern, when the Home Office Race Relations and Immigration sub-committee heard evidence from cities across Britain on ‘racial disadvantage’. Several local groups mentioned SCA, most prominently the submission from the Merseyside Area Profile Group (MAPG), made up of several local black organisations, as well as the local Commission for Racial Equality (CRE) and the Merseyside Community Relations Council (MCRC) – all part of the local infrastructure for race relations management laid in during the first Wilson

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96 Fryer, Staying Power, 397.
97 Bourne, “May We Bring Harmony?”, 89.
Among their evidence of poor treatment was anecdotal evidence of individuals receiving general anaesthesia without being tested for SCA. The coalition stressed that they had applied for the ‘Urban Aid’ fund with a research and awareness-raising project on SCA in 1979, but were turned down. The following year, the Home Affairs Committee – now injected with urgency as a result of the riots – made recommendations to all government departments. DHSS received four, and the only explicitly health-related recommendation was that ‘[a]n explanatory leaflet on sickle cell disease should be produced as soon as possible; hospitals in high-risk areas should consider providing neonatal and adult screening facilities’. Where previously DHSS officials had been remarking on the absence of pressure and resolved to let ‘sleeping dogs’ lie, when this pressure came it was from the infrastructure of local race relations management and black organisations – the local CRE and CRC, mediated through the Home Office Select Committee. Pressure from above and below was being applied.

The following year, DHSS reported to the Home Affairs Committee on the action that had been taken over the SCA recommendation. ‘This recommendation was drawn to the attention of all health authorities in England in October, 1981,’ the memorandum responded. ‘Inner City Partnership Funding has been approved to improve screening and counselling services in Brixton and Hackney in London and similar support is being sought in Liverpool’. It seemed natural for DHSS to pass on the work of screening and counselling services to the Department of Environment and their ICP initiative. Though the ICP had been initially framed as addressing social, environmental and economic problems, by 1979 health was included on the list of priorities – particularly ‘ethnic minority’ health. In 1981, DHSS circulated guidance to Area Health Authorities on applying for funding from the ICP. They advised that proposed projects should be ‘innovative’ or ‘experimental schemes’, targeted at ‘a particular health problem or inner city locality with a certain health

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98 Merseyside Area Profile Group, ‘Home Affairs Committee: Race Relations and Immigration Sub-Committee on Racial Disadvantage – Minutes of Evidence and Appendices’, (House of Commons, 1980): 569.
problem’, or at ‘priority groups in the inner city such as ethnic minorities, the elderly, young people, mentally ill etc… which the NHS has failed to recognise or respond to satisfactorily’. SCA ticked several boxes – services for genetic testing, counselling and awareness raising were underdeveloped and ripe for feasibility testing; it was a condition widely understood to affect non-white groups; and these groups were framed as residing in ‘inner city localit[ies]’.101 A few years later, the Sickle Cell Society recommended that Sickle Cell Information and Screening Centres be set up in areas with ‘a high proportion of at risk population [sic]’, explaining that ‘outside the inner city areas sickle cell disease is sufficiently rare that most doctors never encounter a single case in their entire working lives’.102 Only in inner city areas, they explained, could the necessary level of expertise be generated. By 1985, of the seven dedicated sickle cell centres surveyed by the Runnymede Trust, four were funded by either Urban Programme or Inner City Partnership funding – Liverpool, Lambeth, Brent and City & Hackney.103 Voluntary organisations, in an effort to make SCA services cost-effective and appealing for local health authorities, had to lean into the notion of the ‘inner city’ as a place of need and opportunity for SCA pilots.

In response to the availability of this funding, local health authorities increasingly styled SCA as a natural feature in the ecosystem of urban health. The language that these health authorities used to frame SCA reflects a depoliticization of the condition, a clear sense that in the new environment in which ‘racial disadvantage’ and institutional racism was under discussion, SCA was a ‘disadvantage’ for which the government was not responsible. In 1974, the Merseyside Community Relations Council had contacted the Area Health Officer, a Professor Semple, for screening and counselling for SCA to be provided to Liverpool’s residents. Semple had replied ‘I do not think there would be any justification in a general screening programme being adopted in Liverpool for school children and I think that this would definitely suggest racial discrimination’.104

103 Ibid, 32-41.
However, by 1980 the Liverpool Health Authority was comfortably referring to ‘indigenous conditions and low uptake of services in ethnic minority groups’ as part of the overall picture of inner-city social conditions.\textsuperscript{105} In December 1981 – five months after the Toxteth uprisings – the docklands area of Liverpool known as the ‘Liverpool 8’ was the subject of three health grant applications concerning SCA to the Liverpool ICP.

One of these projects was a research proposal into the ‘health needs of ethnic minorities’ in the area, outlining three strands. The first examined ‘diseases endogenous to particular communities by virtue of inheritance, e.g. sickle cell anaemia in Africans,’ or those ‘as a result of particular practices’, such as diet.\textsuperscript{106} The second strand was ‘specific cultural practices’, which included language barriers, and ‘the effects on health of child rearing practices in West Indians which differ substantially from the norm in Britain’. The third strand targeted ‘the failure of ethnic minority groups to use NHS services’.\textsuperscript{107} Ultimately, this project was approved and granted £20,750 revenue funding.\textsuperscript{108} These strands divided the challenges to ethnic minority health into biological and cultural difference, and integration failure. Health issues of ethnic minorities were attributed to genetic difference, cultural practices, or their ‘failure’ to use NHS services, rather than an absence of funding or interest from the state, or structural issues of poverty and discrimination. Ironically, the 1980 MAPG submission to the Sub-Committee on Racial Disadvantage which had initiated the state’s particular interest in SCA, had explicitly identified ‘poor housing facilities, high unemployment and all other forms of deprivation that plague ethnic minorities in Liverpool’ as possible factors in SCD.\textsuperscript{109} Some contemporaries had warned that this would be an outcome of the Urban Programme. Ambalavaner Sivanandan, director of the Institute of Race Relations, had feared that ‘instead of actually addressing racial injustice, the programme redefined the problem as one of cultural disadvantage and went on to reinforce cultural differences without making any

\textsuperscript{105} Memorandum, Liverpool Health Authority, ‘Health and the Inner City’, TNA AT 81/278/1, 2-3.
\textsuperscript{106} For more on nutrition and migrants, see Bivins, \textit{Contagious Communities}, 234-302; and Roberta Bivins, ‘Re-writing the “English Disease”: Migration, Ethnicity and “Tropical Rickets”’, in Mark Jackson (ed.), \textit{Routledge History of Disease} (Oxford: Routledge, 2016): 257-278.
\textsuperscript{107} ‘Proposal for funding: The health needs of ethnic minorities’, TNA AT 81/278/2.
\textsuperscript{109} Merseyside Area Profile Group, ‘Race Relations and Immigration Sub-Committee on Racial Disadvantage’, 572.
changes to a discriminatory system’. By outsourcing the responsibility for SCA treatment to the DoE’s ethnic minorities funding programme, DHSS created a local environment in which SCA continued to be characterised solely as an ‘endogenous’ condition divorced from the social and economic position of Black British people in Britain.

The DoE soon observed that ICP funds were being used to cover what should have been the normal activities of DHSS. Liverpool ICP complained in October 1982 that ‘DoE is being used by DHSS to subsidise a level of health care in the inner cities which ought to be provided under main programmes’. When DoE raised the issue with DHSS, a DHSS official responded that it was ‘wrong’ to consider such projects to fall into the main programme of the NHS, and that DHSS could not spare more money for the inner cities than their current allocation. DoE officials were unconvinced – one remarked that ‘[he] should be asked to bias his resource allocation to a less modest extent’. However, DoE did not consider SCA to be a service that fell under the NHS main programme. In terms of health projects, SCA fell so neatly within the framework of ‘innovation’ and ‘inner city problem’ that no central or local official considered it to belong to the main programme. However, some local authorities expressed frustration that such short term funding meant essential services were unstable and unpredictable, with only three- or five-year guarantees, and causing ‘obvious problems in terms of the assimilation of successful schemes into the Health Authorities [sic] main programmes’.

Part of the appeal of SCA projects was their association with ‘self-help’. Officials in Lambeth ICP, which funded a Sickle Cell Information Centre from 1982 to 1985, observed that though it was a revenue not a capital scheme (which were preferred), that health schemes were of ‘medium’ priority, and counselling was of ‘low’ priority, ‘[s]uch schemes… with their emphasize [sic] self help and prevention, are considered to be very high priority by the Health Authority’.

**Footnotes:**

110 Bourne, “May we bring harmony?”, 89.
112 Letter, Geoffrey Finsberg to Tom King MP, 24 January 1983, TNA AT/81/278/1.
113 Internal memorandum, Philip Dale to Mr Whetnall, 2 February 1983, TNA AT/81/278/1.
114 R.M., Memorandum ‘Partnership Funding for Health Service Schemes’, 24 February 1984, TNA AT 41/393.
115 Ibid.
history of Asian immigrants in post-war Britain, says that the term ‘self-help’ had gained currency in Black and Asian groups during the 1970s, arising from their activities to provide ‘information, advice, support and education to the members of their communities which the official agencies were either unable or unwilling to provide’.116 ‘Self-help’ was a key tenet of Black Power philosophy, and community work a central part of Black Power groups, and Rosalind Wild argues that Wilson’s Urban Programme had been formulated to target these groups with controlled state funding, neutralising their radicalism.117 Tony Soares, a former member of the Black Liberation Front, told Wild that

The government started a lot of programmes that were intended to buy out the leadership. By the early 1970s it became all grants and Urban Aid… A lot of money was going in, employing people, channelling them into community work and taking them away from political work. They all got caught up in some kind of project or the other because there was money on a scale they’d never seen before.118

SCA was one such community project, and groups dealing with it did receive short-term government funding. It was perceived as a safer issue than many more ‘political’ groups, particularly as many involved in executing these projects were NHS staff who felt constrained in their capacity to criticise the state.

The term ‘self-help’ had been picked up not just by local ICP officials, but also within the DoE itself. The Parliamentary Under-Secretary of State for the DoE, Sir George Young MP, remarked in December 1982 that he was ‘heartened by the number of black self-help groups now well established as a result of IAP [sic] funding’.119 As Florence Sutcliffe-Braithwaite and others have argued, Thatcherism appropriated a mood of individualism emergent in the 1970s into a neoliberal

117 Wild argues that the Urban Programme had tried to avoid the pitfalls of Community Action Programs in the United States, which had left control in the hands of local communities and failed to counter radical ideas. Wild, ‘Black was the colour of our fight’, 172.
118 Tony Soares, interview with Rosalind Eleanor Wild, in Wild, ‘Black was the colour of our fight.’, 173.
119 ‘Minutes of meeting no.10 held on 8 December 1982 at 2.30pm in the county hall’, 8 December 1982, TNA AT/41/395.
agenda. It is tempting to suggest that ‘self-help’ in SCA was a characteristic Thatcherite co-option of a term that would displace responsibility from the state to voluntary groups and facilitate the 1980s agenda of spending cuts. If ‘self-help’ was co-opted, however, then it was done with the participation of SCA activists. The Ghanaian physician and SCA expert Felix Konotey-Ahulu wrote a letter to the *BMJ* in 1982 arguing that only a ‘comprehensive’ approach could tackle the scale of the illness in Britain but that

The responsibility for such a comprehensive approach cannot be left with the central government alone. Local councils with active participation of parents, community leaders and businessmen, self-help groups, local medical and nursing personnel, community social workers, and where necessary adult patients must together be involved with "centres" on the lines recommended by WHO.\(^\text{120}\)

‘Self-help’ came to have connotations of government by consent, and collaboration with ‘self-help’ groups held the promise of generating consensus and buy-in from affected communities. But as Chapters 3 and 4 will argue, these ‘self-help’ groups did not encounter an NHS willing to provide what they asked for, but pushed against an NHS bureaucracy reluctant to spend resources on SCA.

Engagement with self-help groups was a subject of self-reflection and debate within some local councils. In 1982, a meeting of the City & Hackney ICP Officers’ Steering Board reflected on their possibly ‘ethnocentric’ methods of project evaluation, with members invited ‘to consider their overall philosophy regarding monitoring’. A draft paper for the group framed the Urban Programme and the ICP as a marker of the state’s new understanding of ‘the subtlety, variety and depth of racial discrimination in Britain and to evolve an appropriate response’\(^\text{121}\). Lambeth ICP also reflected critically on the criteria by which projects were assessed, and in one meeting decided to take their concerns to the DoE about the criteria’s ‘adverse


discriminatory effects in tackling racial disadvantage’.\textsuperscript{122} The Greater London Council, the Inner London Education Authority, and left-leaning Labour local councils, such as Lambeth, Brent, Hackney and Haringey were the subject of media interest during the 1980s and a target of the Thatcher government.\textsuperscript{123} Several of these councils were led by black councillors such as Merle Amory and Linda Bellos, who were elected leaders of Brent and Lambeth Councils respectively in 1986. Towards the end of the 1980s these councils were defanged by the Department of Environment. A 1987 piece in \emph{The Voice}, titled ‘Inner City Blues’, observed that these changes forced councils to put essential services out to tender and limited their powers over housing – and that the government had spent ‘barely a tenth’ of the budget allocated to the ‘inner-city task forces’.

This section has demonstrated that there was consensus across the board that SCA, and ethnic minority health problems more generally, were considered ‘local’ issues of the ‘inner city’, outside the main programme of the NHS. Services for SCA, caught up in the power struggles between the DoE and DHSS, as well as between the central Conservative government and local Labour councils, suffered from a temperamental flow of small grants. When the Runnymede Trust surveyed the seven sickle cell centres in England in 1985, all but one were funded from local sources, such as the Urban Programme, ICP funding, Community Unit Development Funds, or ‘Joint Funding’ between the council and the LHA. Liverpool and Brent complained of ‘uncertainty about the future due to lack of funding’, Haringey noted that ‘future funding [is] uncertain’ and Manchester reported that they hoped ‘to secure permanent funds from local, regional or national sources because as yet mainstream funding has not been earmarked to maintain or expand the work of the centre’.\textsuperscript{124} No advocacy groups for other genetic diseases were exhorted to ‘self-help’, and no other genetic conditions fell under the remit of the DoE.

\textsuperscript{122} ICU, RCU and DSS, ‘Impact of the Inner City Partnership on the Black Community – An Assessment’, February 1985, TNA AT 41/393.
'The Government is doing its bit': central sickle cell policy, 1982-1996

Until 1980, DHSS viewed SCA as too politically fraught to take a public stance on the issue. Anxieties ranging from a backlash from hospital pathologists to fears of comparisons with a ‘eugenic approach’, as well as complacency about the efficacy of existing informal screening protocols in British hospitals, inhibited any meaningful consideration of a national screening programme for SCD or other central action. Following the evidence from the Liverpool MAPG to the Parliamentary Sub-Committee on Race Relations, the Sub-Committee requested a briefing on SCA from DHSS. In the resulting paper, DHSS washed its hands of responsibility for SCA, citing its politicized nature, its complexity, the lack of remedy, and its varying expression in those affected, as factors which prevented action. However, from 1980 onwards a new tone began to inflect the Department’s discussions around racism. Its previous anxieties centred on eugenics and racism were harder to justify once groups such as the Organisation for Sickle Cell Research (OSCAR), the Sickle Cell Society (SCS) and the Thalassaemia Society were pressing for action. Starting in 1982, DHSS began to grant Section 64 funds to OSCAR and the Thalassaemia Society, and later to SCS. By the early 1990s, however, their newfound enthusiasm had faded. This section will consider this new phase in DHSS policy, as pressure increased upon them to act, and how they engaged with the criticisms levelled against them.

In 1987, Edwina Currie requested that DHSS work with the British Association of Haematologists to produce a ‘haemoglobinopathy card’, and undertake a survey of Health Authorities’ provision for haemoglobinopathy screening. Currie had been closely involved with the Sickle Cell Society, and in March 1987 had presented a cheque for £12,000 (raised at a charity gala) alongside the Society’s patron Lenny Henry, to launch the National Sickle Cell Register. At the event she remarked

Mr Henry’s a scream, but this is such a serious matter. I have been acquainted with the problem for many years, since my days in Birmingham

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125 Bivins, Contagious Communities, 360.
and it is an awful affliction. The Government is doing its bit and we are looking to see how we can help more.\textsuperscript{127}

Currie had been a Birmingham City Councillor from 1975 to 1986. Whether it had been this period, or a more recent political commitment, Currie appears to have been genuinely interested in SCA, and well-liked by some members of the community. In October 1989 Currie received a letter from Marion McTair, of the National Sickle Cell Programme and formerly of the Lambeth Sickle Cell Centre, saying ‘you were the very first Minister to knock the heads of arrogant doctors who have been playing around for years while doing nothing constructive’.\textsuperscript{128} Internal documents suggest that the civil servants within DHSS had suggested that the survey be part of a ‘more general circular which had been planned to look at genetic screening and counselling services as a whole’, but this had been ‘dismissed’ by Currie, although (the official editorialised) she had ‘no clear idea of the kind of help she intended giving’.\textsuperscript{129} In the 1988/89 review of the work programme for the workstream ‘CMP1C’ (which covered maternity services and child health), the SCA screening and counselling services review was described as a ‘Major Task: Theoretically postponable but strong Ministerial pressure’.\textsuperscript{130} By this point the Department had received over 170 responses from health authorities, and an official noted that they indicated ‘a range of practices’ across the country.\textsuperscript{131} However, in December 1988 Currie resigned following her comments about salmonella in British eggs, and DH officials began to quietly shelve the issue. By November 1989 – less than a year after her resignation – a DH official commented to others that ‘as yet we have not been able to provide the resources to complete the analysis of the results’, but that ‘[w]ith the burgeoning interest in the generality of genetic screening we now plan to include the haemoglobinopathies in an overall review of genetic services’.\textsuperscript{132}

\textsuperscript{127} ‘Two of a kind steal the show: Lenny and Edwina’s comic double act’, \textit{Daily Mail}, 24 March 1987, Daily Mail Historical Archive.
\textsuperscript{128} Letter, Marion McTair to Edwina Currie, 18 October 1989, TNA JA 418/6T/Z/1.
\textsuperscript{129} Letter, N.F. Duncan to Mr Hale, ‘Sickle Cell Anemia’, 25 August 1988, TNA JA 418/6T/Z/1.
\textsuperscript{130} Internal memorandum, ‘CMP1C section management account, 1988/89’, TNA JA 418/6T/Z/1.
\textsuperscript{131} Letter, Elaine Edgar to Mr Duncan and Miss Burdon, 9 December 1988, TNA JA 418/6T/Z/1.
\textsuperscript{132} Memo, J.C. Read to Mr Heppell, Mr Hale and Dr Lister Cheese, 27 November 1989, TNA JA418/6T/Z/1.
Despite officials’ reluctance to engage with the survey, it continued to be used to illustrate their ongoing commitment to improving services for SCA. In January 1989, they responded to a Private Members’ Bill pushing to make screening for haemoglobinopathies mandatory citing the survey as the first step in discussions with health authorities on the development of such services. The same formulation was used in answer to a Parliamentary Question about local funding for SCA, and to enquiries from OSCAR in the same year, though officials noted internally that ‘[t]he reference to the Department’s questionnaire to health authorities…has been kept deliberately short since I understand that decisions have still to be made… on whether the information is published and on any future action’. Paul Boateng MP, a supporter of SCS, asked two Parliamentary Questions in 1989 about the progress of the survey report. He was first told that it was ‘nearing completion’, but was later informed that ‘pressure of other work has delayed completion of the analysis of the results of this survey’. DH reformulated its commitment to SCA to a broader commitment to genetic services, explaining that ‘it remains our intention to review present provision for counselling and genetic diagnosis and screening – including that of sickle cell disease and thalassaemia – and consider the need for further central guidance.’

This shift away from an already reluctant focus on haemoglobinopathies towards a more generic commitment to genetic conditions more generally suggests a strand of thought within DH that was critical of ‘special treatment’ for ethnic minorities. In March 1990, Dr P.R. Greenfield of DH responded to an article by haematologist Eric Stroud, which made the case that ‘children with [haemoglobinopathies] appear to be getting a raw deal, both regarding screening

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133 Letter, Roger Freeman to Tony Lloyd MP, 19 January 1989, TNA JA 418/6T/Z/1. The bill was presented by Tony Lloyd and supported by Keith Vaz, Paul Boateng and Bernie Grant; former Parliamentary Under-Secretary of State for DHSS, Conservative MP Sir George Young; and Dafydd Wigley, a Plaid Cymru MP who lost two children to the inherited condition Sanfilippo Syndrome. See Emily Woodrow, ‘Elinor Bennett Wigley talks about her new autobiography’, Wales Online (26 March 2013), https://www.walesonline.co.uk/news/local-news/elinor-bennett-wigley-talks-new-2033873
and follow-up of positive cases so identified’. Greenfield, in response, strongly rejected the notion that the Government were accountable. The article, he said, has highlighted one small area of child health care where services appear to be inadequate, and it is largely for the profession, rather than central Government, to put their house in order. The article could have been written about a number of different chronic conditions of childhood, and similar inadequacies would almost certainly have been found[.]

He subsequently noted that his was a ‘somewhat extreme reaction’ which he had ‘got off his chest’, suggesting it was a contentious, ongoing issue about which he felt strongly. In March 1991, a Camberwell Community Health Council official wrote to Stephen Dorrell MP, the Parliamentary Under-Secretary of State for Health, again asking about the 1988 survey. ‘[W]e have never seen any results,’ he observed, and asked how many districts had routine neonatal and antenatal screening programmes, and for comparisons between resources for haemophilia and SCD. Dorrell responded to the implied comparison between haemophilia by saying that

There was also evidence to support the view that screening and counselling services for the haemoglobinopathies have fared better than have services for other genetic disorders. Clearly, the fact that the population at risk is more readily identifiable by the nature of their ethnic background (Caribbean, Asian, Mediterranean etc) has helped in this and for that reason, universal screening would be neither appropriate nor cost effective.

Dorrell challenged the implications of institutional racism by suggesting that the exceptionalism of the haemoglobinopathies was an advantage, while other genetic diseases (implicitly those affecting white people) had been neglected. His use of

‘clearly’ and ‘identifiable’ hinted at the visible difference of ‘Caribbean, Asian, Mediterranean’ people, which he suggested singled them out for advantage and better treatment, rather than worse. His message was clear: that haemoglobinopathies had received enough attention, and now it was time to address the needs of other genetic conditions. Michael Sullivan argues that Thatcher and John Major’s governments ‘were determined to change the nature of the debate around the NHS and to change the institution itself’, aligning with a neoliberal ideology that ‘questioned the legitimacy of using government policy as a health equality machine’. 140

As SCA and thalassaemia organisations began to press for action in the early 1980s, the Department began to defend itself against accusations of institutional racism by citing the ‘special treatment’ that the haemoglobinopathies had already received, though a decade previously officials had been avoiding action on the condition due to its politicized and racialized nature. However, the tide turned against them and in the early 1990s, SCA policy was taken forward within DH under the ethnic minority health banner, led by Veena Bahl, DH’s advisor in ethnic minority health. 141 Gradually, experts from the local SCD centres that had developed in local areas such as Brent began to contribute directly to DH policy, and in 1993, a Standing Medical Advisory Committee on haemoglobinopathies – including representatives from local centres, voluntary organisations and patients – produced a report which proved that patients with SCD in England often received poor treatment. 142 It found that children with the disease did not always receive penicillin prophylaxis, though it was one of the few interventions supported by research. One doctor explained that the services were in a ‘similar situation to where haemophilia services were 20 years ago’. 143 The report made 62 recommendations to improve services, but experts expressed disappointment that ‘it gives advice rather than

143 L. Dillner, ‘People with sickle cell disease need better services’, British Medical Journal 308, 616 (5 March 1994).
binding recommendations to purchasers, it sets no date for implementing its recommendations, and it identifies no new money to fund them'.

**Conclusion**

In the 1960s and most of the 1970s, DHSS explained their inaction by pointing to the adverse effects that drawing attention to the condition might have – marking those with the trait or disease, or black British communities as a whole, out as ‘even more’ different than how they were already perceived. Citing the risk of appearing to support ‘eugenic’ policies and of possessing other ‘sinister’ motives, with a general distaste for targeting individuals on an overtly ‘racial’ basis, the Department avoided putting their name to any publications or recommendations on the matter, and sought to use doctors as their policy mouthpieces. The preferred policy line was that of unspoken screening, through recommending that doctors quietly avoided general anaesthesia in African or Caribbean patients. This, combined with reluctance to affront professional groups within the NHS – particularly pathologists – ensured that no public action was taken by DHSS in this time.

By the late 1970s and the early 1980s, particularly in the wake of the 1980-81 uprisings, with advocacy and community groups hitting their stride (see Chapter 4), DHSS came under some pressure from the Home Office to take action on SCA. Gary Craig has argued that ‘the British state is only marginally concerned with the welfare of minorities and acts energetically only in response to serious crises, such as occasional urban disturbances, or to the vigorous campaigning of minority organisations’. While the priority remained the avoidance of the appearance of racism, policymakers increasingly understood that worse than the acknowledgement of a genetic disease which predominantly affected black communities, was institutional indifference. However, DHSS shifted this responsibility to the Department of Environment and to local councils with the short term funds of the

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Urban Programme – illustrating the extent to which SCA was still considered to be a ‘special case’ outside the remit of the Department of Health and the NHS main programme. When action was taken – such as the issuing of haemoglobinopathy cards in 1988 – it was taken at the behest of the Minister. With enquiries increasingly comparing the provision for SCA with that of other genetic conditions, DHSS was split between those who saw it as a case that needed particular attention to counteract the ignorance of the health service, and those who saw it as having already been allocated more than its ‘fair share’, and as having actually benefited from the ‘distinctiveness’ of the affected population.

This chapter has delineated the voices within the British welfare state – both those who argued that something needed to be done, and those who asked, why sickle cell? Through this period, officials’ changing views on what constituted racism – first a biological racism which emphasized physical distinctiveness and ‘disease’, then institutional racism and indifference to black health – shaped their internal discussions, and slowly shifted their inertia into limited forms of action. However, their continued distancing of the subject away from Whitehall policymakers to local pilots and ICP funding resulted in a patchy service for which they could evade accountability. Central inertia led to confusion, anger and action on the ground, as the next chapter will show.
Chapter 3: Seeing like a welfare state: Race, visibility and legitimacy in NHS sickle cell services, 1973-1997

On 23 April 1956, Dr Montague Maizels of the Clinical Pathology Department at University College Hospital wrote to the Colonial Office asking for ‘A. The number of West Indians who have entered this country, yearly, for the past five years’, and for ‘B. The proportion of males and females’. He explained that he had found seven West Indian patients carrying the sickle cell trait, ‘and clearly we must expect to have many patients with sickle cell disease in this country in the near future.’ Maizels’s line of questioning implied, through asking about the proportion of men to women, that those with the disease would not necessarily arrive by plane or boat but would instead be born on British soil, to West Indian couples who would start families. However, this implication was lost on, or ignored by, the Ministry of Health, to which the query was referred. The Ministry’s answer confused the sickle cell trait, (which is asymptomatic) with the disease, and confused the disease itself with another blood disorder. A Home Office official nevertheless responded with relief that ‘[t]he medical advice you have given suggests that the position may not be so serious as Professor Maizels’ letter implied’. Maizels’s letter is the first source on record for sickle cell anaemia in a British clinic, and he attempted to notify the state that a condition considered in this period to be a ‘tropical disease’ would soon become a domestic issue. However the central state and its health ministries issued no clinical standards on the condition until 2008, and in the forty-nine years between Maizels’s first letter to the Colonial Office and 2005, no National Screening Programme was implemented – although a simple genetic test had been available since the late 1960s.

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4 In 1993 DHSS released a Standing Medical Advisory Council report on haemoglobinopathies, with 62 recommendations but no binding recommendations or additional funding. Department of Health, Report of a working party of the Standing Medical Advisory Committee on Sickle Cell, Thalassaemia and other Haemoglobinopathies (London: HMSO, 1993). Clinical standards were not issued until 2008. Sickle Cell Society Standards for Clinical Care of Adults with Sickle Cell Disease in the UK
Chapter 2 showed that, throughout the period, DHSS/DH were reluctant to issue directives to the service – disavowing the responsibility of central government in matters concerning the medical profession. As Rudolf Klein has observed, a theme in the history of the NHS since its birth has been a cycle of experiments with centralization and delegation, and a tension between local health services’ accountability to local needs and Ministerial accountability to Parliament.\(^5\) Whitehall, therefore, is only part of the story. This chapter argues that many local NHS actors were able to sidestep accountability and justify inaction by simply not ‘seeing’ sickle cell at all. James C Scott has examined how states, in attempting to enact utopian systems to improve the human condition, seek to render their populations ‘legible’ through the imposition of categories and the collection of information.\(^6\) The National Health Service – promising free healthcare for all – was a utopian vision, but as postcolonial historians have recognized, the British welfare state is threaded with the afterlives of empire. Health commissioners made black communities ‘legible’ through focusing on what they saw as social issues, obscuring their medical needs. In response, efforts by specialist medical personnel to build services for SCD focused first and foremost on making the condition visible, and one that therefore needed to be factored into local commissioning. These doctors, nurses and health visitors sought to reframe the state’s forms of legibility through work and participation in the institutions of the state.

From the 1970s onwards, small groups of healthcare professionals were engaged in local work which came to underpin the assumptions behind the national frameworks of the 2000s. This chapter will argue that while DHSS and the MRC were debating and delaying the awkward questions of race and pathologists’ workloads, a localised and patchy provision for sickle cell was being developed by local nurses, health visitors and haematology departments. This meant that many

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services were unknowingly engaged in what the RCP described as ‘wasteful duplication of effort, and though a consensus view on the best approaches can be developed only by pooling experience, information is still not integrated at a regional or national level’. The lessons learned from these services were eventually central to the national policies that began to take shape in the early 1990s. The introduction of national screening was founded upon what had already been achieved by local services, using intelligence gathered and research conducted by those local services.

Rudolf Klein has memorably summarised the historical arc of the NHS as that of ‘church to garage’ – from the evangelical faith of Old Labour to commercial Conservatism, ‘from paternalism to consumerism, from need to demand, from planning to choice’. This shift towards the treatment of the patient as a consumer, whose rights and feedback hold significant sway over NHS provision and incentives, has been explored by Alex Mold in her work on the developing role of the ‘patient-consumer’ in the NHS from the 1960s onwards. She describes a trend in which patients moved from the periphery to the centre of NHS care – from the ‘doctor knows best’ approach of the 1960s to the ‘no decision about me, without me’ philosophy of the 2010s. As improvements in the treatment for SCA have often been framed as patient-centred approaches, elevating patient voices to challenge institutional inertia, this case study suggests this shift towards consumerism within the NHS was one which could – at least superficially – incorporate anti-racist critiques. However, the historiography has identified several ‘subaltern narratives’ within the NHS that escaped this broad shift from paternalism to consumerism, such as psychiatry and long-term care for the elderly. Andrew Scull argued that the fiscal stresses of welfare capitalism fell on ‘problem populations’ perceived as unproductive, such as the mentally ill. Accordingly, this chapter both situates the

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narrative of SCA within this broader movement for patient-responsive care in the NHS from the 1960s onwards, and observes that patient groups who were considered problematic could be left behind in this movement.

A case study of SCA within the NHS enables an exploration of how these shifting discourses around citizenship and ‘race’ shaped encounters between doctors and patients, and between the NHS bureaucracy and Caribbean, African and Black British nurses. By examining the discussions and emerging provisions for SCA within the spaces of the NHS, this chapter will explore how migrant and Black British communities’ entitlement to care from the state was challenged and litigated through discussions around screening, counselling, funding and treatment. This chapter will first consider how doctors and local health authorities dealt with the question of SCD at the level of planning and policy during the 1970s and 1980s. These discussions asked whether or not it was a problem, where it was, and what could be done about it. This discourse was shaped by questions around geographical and cultural assimilation and the relative ‘whiteness’ of the majority of the British population. The second section will examine how these discussions around the geography of migrant settlement resulted in a new model for the treatment of SCD ‘in the community’ – local haemoglobinopathy centres based in ‘multicultural’ areas. These centres developed clinical consensus for the treatment of SCD (and its sister condition thalassaemia) and a research base that led to the improvements of the 1990s. The third section will explore contact between SCD patients and medical personnel in hospital wards during the painful crises characteristic of sickle cell, and explore how clinical treatment could be influenced by racist stereotypes linking black people and drug addiction. During the 1980s, the burgeoning expertise of the local sickle cell centres and specialist healthcare professionals acted to represent the interests of SCD patients and to legitimize their experience, symptoms and pain.

Hidden in plain sight: SCA screening pilots in the 1970s

Few sources exist that deal with the diagnosis, treatment or experience of SCA in British medical spaces in the 1950s and 1960s. An understanding of Britain as a ‘white country’, and SCA’s racialization as a primarily ‘African’ or non-white trait
precluded researchers, doctors and policymakers from considering it relevant, and the archive reflects this thinking. Healthcare professionals and experts engaging with the issue of SCD geographically delimited the condition to Africa, India, the Middle East and the Caribbean. The 1964 film ‘Sickle Cell Anaemia in Nigeria’ was produced for the education of British doctors and other medical personnel. As the film explained the mechanism of the sickle cell mutation, a map of Africa was shown on screen with the belt shaded red to indicate malaria. This was followed by a second map, this time of the world, featuring shaded areas to indicate the incidence of SCA. In addition to the sub-Saharan belt, also shaded was Italy, Greece, Turkey, Yemen, south India and the Caribbean, overlaid with white arrows to indicate that SCA could be found ‘wherever men of African descent have migrated’.¹² North America and Britain were left untouched. By the time this film was made, Commonwealth migration to the metropole (from many of these shaded regions) had been underway for over fifteen years with an estimated 900,000 migrants from former colonies residing in Britain, and of course African-American populations in the

United States had been present for centuries.\textsuperscript{13} The message of this educational film, however, was that SCD was not a domestic issue. Twelve years later, the 1976 edition of \textit{Genetic Counselling} claimed that SCA ‘is not of great consequence to us in the context of genetic counselling in the United Kingdom’, because the condition is ‘confined to peoples of African and Eastern origin’.\textsuperscript{14} These medical texts conveyed a racialized and geographical understanding of SCA, which rendered the condition largely invisible in Britain until the late 1960s, shaping the responses of healthcare professionals to cases of SCD in NHS spaces, and structuring the archives of the condition.

This invisibility of SCD in the training of British doctors also had ramifications for the structure of hospital wards, where the scale of the problem frequently went unnoticed even when they were housing multiple SCD patients. Haematologist Milica Brozović, upon her arrival to her new job at Central Middlesex Hospital in Brent in 1975, encountered several SCD patients and inquired among her colleagues about a dedicated service for them. She recalled that fellow staff were surprised, told her that there were very few SCD patients, and estimated she would only need two beds. But Brozović found when she began the exercise that there were ‘sickle cell patients in every ward… they were there, just kind of hidden, ignored’. Each had been diagnosed, but each was cared for by a different consultant and team. ‘[T]hey were all there physically, but because Doctor So and So admitted one, and Doctor So and So next day admitted two,’ Brozović said, ‘the impression was that there were very few, because they were never concentrated in one place’.\textsuperscript{15} Within six years, Brozović and her colleagues identified 68 people living with SCD in Brent alone. The racial and geographical framing of the condition as not British, and therefore not in Britain, meant that each patient was labelled an unusual outlier and could not be identified as part of a larger pattern. Without this pattern, arguments could not be made for service provision.

The primary intervention considered for genetic conditions in the 1960s and 1970s was screening. The UK’s first genetic screening programme, for the metabolic

\textsuperscript{14} A.C. Stevenson and B.C.C. Davison, \textit{Genetic Counselling} (London: Heineman Medical, 1976).
\textsuperscript{15} Milica Brozović, interview with author, 22 October 2018.
disorder phenylketonuria (PKU), had been rolled out in 1968. When a child was found to have PKU, they were placed on a phenylalanine-restricted diet, protecting them from physical and intellectual disability. The 1970s onwards also saw the development of regional genetics centres which sought to integrate genetic services into the NHS, but as this chapter will show, the picture was more complex for SCA.

Medical professionals identified many barriers to universal newborn screening for SCA, including the justification that the SCA was so rare that screening would not be cost-effective, uncertainty about follow-up interventions, concerns about the appearance of racism and eugenic policy when screening on the basis of ‘race’, and damaging stereotypes about Caribbean and African people and families and their suitability for health intervention and education.

When healthcare practitioners began to take action on SCD, it was often because of their impressions of their local areas as one with high migrant populations. The distribution of migrants was a subject of analysis and political tension in post-war Britain. Social scientists and policy researchers researched the subject from the early 1960s. Sheila Patterson devoted a section of her study of the Caribbean community in Brixton to ‘[t]he ‘ghetto’ and its consequences’, writing that ‘[i]n spite of overcrowding and physical discomfort, the incipient ‘ghetto’ in which most West Indians live in Brixton eases the immediate processes of adjustment and adaptation for the newcomers’. As this suggests, geographical distribution became a key proxy measurement for social scientists to read the extent to which these newcomers intended to integrate into British ‘ways of life’, or exist in separate enclaves, living according to ‘foreign’ cultural standards. Enclaves of migrants from the Caribbean in particular alarmed sociologists. They feared the impact of such separation between the groups of the ‘host’ and the ‘stranger’, and argued for efforts to enable contact. Michael Banton warned that “harmonious relations between the two groups” could not be obtained "by the creation of English Harlems.”

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17 Patterson, Dark Strangers, 213.
18 Michael Banton quoted in Waters, ‘Dark Strangers’ in our midst’, 231. Other sociologists stressed that that urban areas with high migrant populations were often the result of discriminatory rental practices – a 1967 Political and Economic Planning (PEP) investigation into the London rental sector found that only 11 per cent of advertised rentals did not exclude black and Asian people. See James Hampshire, Citizenship and Belonging: Immigration and the Politics of Demographic Governance in
local councils used high immigrant numbers to justify withholding, rather than providing, services. For example, in 1970, a Birmingham City Council clerk complained to a parliamentary select committee that the high numbers of immigrants who had settled in the area was negatively impacting their council housing programmes. ‘We just cannot house our own population there now’, he argued, while the city’s medical officer of health proposed that ‘there are many areas of this country that do not know this problem whatsoever, and you may consider it would be quite reasonable and sensible and fair for immigrants to go to those areas’.\(^1\)

The government took action in the 1970s to prevent migrants from settling in cities seen to have ‘too many’ migrants already: in 1972, Ugandan Asian refugees were encouraged to settle in ‘green zones’ where the Asian population was considered so low that their arrival would be ‘tolerated’.\(^2\)

With the concept of the ‘immigrant area’ so prominent in Race Relations research and policymaking in the 1960s and 1970s, one might assume that the case for health services such as SCA screening would have been apparent. Yet, many Health Authorities in places that otherwise insisted that they had too many migrants did not see the need for haemoglobinopathy screening.

For one thing, accurate statistical estimates of the at-risk communities were often flawed. Studies attempted to gauge the size and locations of the populations at risk from SCA by combining estimates of ethnic minority populations, and rates of prevalence within these populations.\(^3\)

Figures from the national census often constituted administrators’ and medical researchers’ only options, but doubts about the accuracy of these figures with respect to immigrants were raised early on. In a 1969 article in the race relations journal *Race*, titled ‘Locating Minority Populations: A Research Problem’, one Ernest Krausz warned that ‘much doubt has been voiced about for instance the reliability of the 1961 census data so far as coloured

\(^1\) From the Select Committee on Race Relations, quoted in Feldman, ‘Migrants, Immigrants and Welfare’, 98-9.


The number of cases of sickle-cell disease in English and Welsh cities and towns from which cases were reported. The NHS regional boundaries are indicated.

immigrants are concerned’. Mistrust on the part of the respondents in terms of ‘secrecy’, as well as ‘a desire to conceal over-crowded living conditions’, were given as reasons that many from the New Commonwealth evaded notice.²² By 1981 the ‘increasing size of the British-born ethnic minority population’ meant that Census compilers – nervous of the response from a community routinely questioned about their ‘entitlements to citizenship and social services’ – rejected a question explicitly on ethnicity for one requesting the respondent’s birthplace.²³ Healthcare researchers and professionals attempted to use these varying census figures to design and support local interventions for population-specific conditions such as the haemoglobinopathies, but acknowledged the drawbacks of this approach. A 1985 report by health visitor Elizabeth Anionwu and the haematologist Milica Brozović accepted that, while they had used the 1981 census (which used birthplace as a proxy for ethnic origin) as a guide for ethnic minority residence, figures tend to be ‘an underestimate in urban areas (where there are the longest-established ethnic minority communities) and an overestimate in towns with large numbers of retired residents or with military connections (where there are proportionally more white people who were born in the New Commonwealth or Pakistan)’.²⁴ However, even where it was accepted that there were high migrant communities, the implementation of long term screening could be frustrated.

Clinicians at both Royal Manchester Children’s Hospital and Birmingham Children’s Hospital began neonatal screening pilots for haemoglobinopathies in 1973.²⁵ Both pilots were justified on the basis of the regions’ high migrant populations, calculated ‘there were 102 000 children in school in Manchester in 1973, of whom 6342 (6%) were listed as immigrants… The racial distribution would be the same as that of their parents, so half would be of Asian and half of Negro

²³ Bivins, Contagious Communities, 363.
(African and West Indian) origin’. The Manchester study made an estimate, using school records of migrant children to estimate how many ‘Asian’ and ‘Negro’ babies would be born in Manchester each year, and to estimate that 17 to 26 babies would be born with the sickle cell trait. They picked up 27 such babies, but less abnormal haemoglobins as a whole than they had anticipated, and the authors concluded that ‘it must be because the immigrants, though noticeable because of their colour, are still only a small minority’. The implication was clearly that their expectations of abnormal haemoglobin frequency were informed not just by the percentage of ‘immigrant schoolchildren’ and scientific studies on haemoglobin frequencies, but also by a visual awareness of the numbers of migrants presumably seen by the study’s authors in the public and healthcare spaces of Manchester.

Webster has written about this notion of the ‘visibility’ of ‘coloured’ migrants as leading to an exaggerated sense of their predominance in a local area. Pre-1945, the term ‘immigrant’ commonly referred to the Irish or Jewish populations; post-Windrush these groups gained comparative invisibility after the arrival of black and Asian migrants from former colonies. The change in the meaning of ‘immigrant’, Webster argues, ‘produced a characteristic opposition between Britishness as white, and “immigrants” as “coloured”’— even though, during the late 1950s the numbers of Irish migrants were almost double those from the Commonwealth.

The Manchester study tested every baby born in the hospital, piggybacking the test onto the existing PKU screening programme. Where an abnormal haemoglobin was found, the family’s general practitioner would be contacted for ‘helpful details about the baby such as its racial origin, its health and that of its family, the attitude of the mother, and the family background’.

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26 Evans and Blair, ‘Neonatal screening for haemoglobinopathy’, 129.
27 There are a range of abnormal haemoglobins which can interact with the sickle cell trait, including beta-thalassaemia and haemoglobin C. D I K Evans, and V M Blair, ‘Neonatal Screening for Haemoglobinopathy Results in 7691 Manchester Newborns’, Archives of Disease in Childhood 51 (1976): 129.
‘origins’ enabled them to draw conclusions about the ‘White’ as well as ‘coloured’ population of Manchester, finding that

[n]early all of the abnormal haemoglobins were found in coloured babies… These findings contrast with those of Schneider et al in about the same number of American ‘White’ babies of whom 76 showed an abnormality… Their findings reflect the mixed racial background of an American population. By the evidence of our study the White population of Manchester has very few genes for haemoglobin disorders.\textsuperscript{31}

The use of quotation marks when referring to ‘American ‘White’ babies’, where they were absent in describing ‘the White population of Manchester’, indicates the continued racialization of the sickle cell trait as having the power to reveal a hidden ‘mixed racial background’ beneath ‘White’ skin. Bill Schwarz has written about the impact of decolonisation during the 1970s upon the experience of ‘whiteness’ in the metropole, and argued that this, combined with black migration, served to ‘unsettle English ethnicity’ during the 1960s and 1970s.\textsuperscript{32} In this context, the Manchester sample reads as a defensive rebuttal against this unsettled Englishness. This racialization had implications, as the Manchester study was discontinued after only one year despite picking up more cases of sickle cell trait than initially predicted, on the grounds that ‘such a programme would be justified only in areas where haemoglobinopathies are common and a significant number would be found’. Their white population, it was implied, was too white ‘to justify its continuance’. The opposition between the ‘growing immigrant population introducing a wide variety of abnormal haemoglobins’ – who were implied to be ‘coloured’ – and the white population of Manchester, implied to have fewer abnormal haemoglobins than white Americans – set up an opposition between Blackness and Britishness at the level of the gene.\textsuperscript{33}

\textsuperscript{31} Ibid, 130.
\textsuperscript{33} D Evans et al, ‘Neonatal screening for haemoglobinopathy Results in 7691 Manchester newborns’, 130.
The authors of the Birmingham study concluded by saying they were evaluating the West Midlands region to see if the programme could be extended to other areas, but that ‘[s]everal health districts have so few babies at risk that this is clearly not justified’, and suggested that such districts could undertake targeted screening ‘of the babies at risk only in each maternity unit’, which would be ‘more cost effective than comprehensive population screening’\textsuperscript{34} This selective screening would mean only pregnant women who were read as ‘non-white’ would be tested for SCA. Doctors therefore weighed cost-efficiency concerns, and emphasized selective rather than universal screening, according to a sense of Britain and its population as having lower frequencies of abnormal haemoglobins than other countries such as the United States, ignoring the implications of interracial relationships and mixed heritage children.

The Manchester pilot also gave the authors an opportunity to assess the suitability of families for counselling when their child was found to have the sickle cell trait rather than the disease. This became another justification for the cessation of the programme – that ‘[i]t is impossible to get informed consent for a blood test if parents cannot understand its purpose… some investigations were not done because we believed that more blood tests would only increase parental anxiety without helping the baby’. They concluded their assessment of immigrant families by warning, ‘[m]any of the fathers were not tested because the mothers were not married’.\textsuperscript{35} In 1974, one of the authors – D.I.K. Evans – rebutted a \textit{BMJ} editorial recommending local services and screening for haemoglobinopathies, arguing that ‘[a]ny screening programme will detect far more carriers than homozygotes, and there are real difficulties with the information thus gathered’. Evans had found in Manchester that though six mothers of babies with the trait were nurses, ‘[o]nly two knew about sickle-cell disease… from their nurse training, not their personal experience’. Though he drew attention to the limited coverage of SCD on the nursing curriculum, he strongly implied that Afro-Caribbean and African communities were

\textsuperscript{34}P Griffiths et al, ‘Evaluation of eight and a half years of neonatal screening for haemoglobinopathies in Birmingham’, 1585.
\textsuperscript{35}D Evans et al, ‘Neonatal screening for haemoglobinopathy Results in 7691 Manchester newborns’, 130.
primarily at fault for being uninformed about the disease in their ‘personal experience’:

Parents cannot understand the genetic implications of being carriers if they know nothing about the disease in question. If a programme of screening and education is to have a chance of success it must be run by black people and the impetus should come from the black community, but there are few individuals who could organize an educational programme in the black community here. In parts of the world where sickle-cell disease is common this must be less of a problem. Konotey-Ahulu has described 15 different terms for sickle-cell disease in Ghana, familiar even to illiterate grandparents.36

Evans’s implication – although the majority of the black people residing in Britain would have been first generation migrants at this time – was that, in the act of migrating from Britain, these people had lost their knowledge of the disease, whereas in countries such as Ghana it was ‘familiar even to illiterate grandparents’. Without this pre-existing knowledge, Evans implied, it was impossible for British doctors to explain the condition to black parents.37 Jordanna Bailkin, when considering the responses of social scientists and administrators to African and Caribbean approaches to childcare and parenting, characterised their research question as: ‘Was the African family pathological in its indigenous environment, or had it been warped by the process of migration?’38 In this case, the answer advocated by those who discouraged neonatal screening was ‘both’. Evans seemed to suggest that indigenous environments had endowed Britain’s black populations with this disease through exposure to malaria, and now in the process of migration their suitability for genetic counselling had been annulled by the severing of their connections to the folk knowledge and ‘illiterate grandparents’ of their homelands.

‘Nor are our doctors better informed’, Evans went on to say: ‘[i]t is not surprising; few doctors have any personal experience of these cases’. In Britain, effective counselling for SCA was geographical, as he wrote that ‘[i]n parts of the world where sickle-cell disease is common this must be less of a problem’. Furthermore, Evans challenged the notion of defined geographical areas for targeted screening, observing that the immigrant community in Manchester were also not amenable to screening and counselling because of their settlement patterns: ‘cases [of the trait] were not registered with a small nucleus of doctors in an immigrant area; the 29 babies were on the lists of 29 different doctors.’ The clear message was pessimistic: such a rare and foreign condition could not be effectively treated in a fragmented and ignorant migrant community by an English health service staffed with white doctors; but only in its countries of origin, implicitly with folk medicine passed down through generations. Moreover, he declared, ‘few individuals... here’ in the black British community would be capable of organising such a programme.39 Fourteen years later, writing in her thesis entitled ‘Health education and community development for sickle cell disorders in Brent’, the health visitor Elizabeth Nneka Anionwu drily remarked that Evans ‘does not expand upon his reasons for making such a sweeping statement’.40 In this way, black communities were both infantilised and blamed by health authorities and experts for the absence of sickle cell provision.

Even in diverse areas, advocates for SCA screening struggled to convince Health Authorities to undertake selective SCA screening. Milica Brozovič asked the North West Thames Regional Health Authority – which included Brent and Wembley, two boroughs with some of the highest ethnic minority populations in London – for funds for a selective screening programme. Brozovič recalled that the Authority refused, saying ‘look, we do not have that many, it is not cost effective to do it’.41 A 1971-75 survey of live births in London boroughs had shown that in Brent (which is included in this particular health authority) 38% of live births were born to mothers

39 Evans’s emphasis on impetus coming from the black community likely came from the American example. During the 1960s, sickle-cell screening programmes emerged in tandem with the Black Power movement, and such centres were directed and staffed by members of the black community. See Duster, Backdoor to Eugenics, 46.


41 Milica Brozovič, interview with GR, 22 October 2018.
from the New Commonwealth and Pakistan – the highest in London. Brozović and her colleagues focused, as a result, on proving that ‘we did indeed have that many, that we had more than Tay Sachs… more than Down’s Syndrome’, and undertook a pilot screening programme at the Central Middlesex maternity unit. The estimated cost was £20,000, which was considered ‘exorbitant’, so Brozović conducted the study out of their existing budget, remembering they had to ‘squeeze here, squeeze there, but it was a hard battle’. Catherine, a community paediatrician, had a similar experience, when she asked her Local Health Authority to trial newborn screening for SCA when she was based in Paddington. The LHA were so reluctant that she and her manager cut costs by volunteering out of hours to conduct genetic counselling and outpatient follow-up, and through performing only selective screening.

Selective screening proved ineffective, Catherine explained, because skin colour was not an accurate predictor for haemoglobinopathies, selective screening relied on healthcare professionals making uninformed judgements about a mother’s ethnic background, and because it could not identify if a white mother had a partner in an ‘at risk’ group. ‘You’re bound to miss some,’ Catherine said, especially as health workers did not have time in consultations to ask in-depth questions about a pregnant woman’s ancestry. She described a ‘fair-haired, blue-eyed’ British man who had turned out to have the sickle cell trait when tested at a London hospital in the 1980s. ‘[H]e was so arrogant’, Catherine remembered. Imitating his reaction, she said ‘You’ve got it wrong! Can’t be! Haven’t got any black blood in my family!’ The man demanded to have the test done again, and again it came back ‘AS’ (the trait).

This individual’s outrage at the news of his sickle cell trait is an interesting suggestion that its racialization in Britain had publicly marked it as a test of racial purity. This patient angrily asserted his white ‘blood’ to a group of black nurses, who retested him to get the same result. Simon Dyson found in his interviews with 27 haemoglobinopathy counsellors that it was common for white English people identified as carriers of the SCA or thalassaemia trait to react with anger or distress

43 Milica Brozović, interview with GR, 22 October 2018.
44 Catherine (pseudonym), interview with GR, 9 December 2018.
to the news, describing themselves as ‘tainted’ or ‘contaminated’ by a disorder they have linked to being ‘black’. These counsellors were often themselves black, and endured racism in dealing with these patients’ negative reactions. American physicians in the 1920s and 1930s found sickling in white Americans, and evolved a third concept of ‘apparently’ but not truly white people, treating the sickle cell trait as a ‘means of raising doubts about the legitimacy of certain people’s claim to whiteness’. These instances of white British people being shown to have sickle cell trait could not break the link between SCA and ‘race’, and Health Authorities continued to insist on selective screening.

These selective screening programmes, in screening only mothers, meant that the programmes were only looking for instances of SCD, rather than the trait. Health Authorities and health professionals expressed reluctance to extend the screening programme to pregnant women’s partners, and were pessimistic about informing families if their child had the asymptomatic trait. Health visitor Elizabeth Anionwu, from the Brent Sickle Cell Centre, recalled a meeting initiated by the Camden & Islington Health Authority in June 1981. Despite their enthusiasm in setting up the meeting, Anionwu writes that it quickly became clear that the officials considered local services for SCA to be already ‘adequate’. They had a screening programme for women in SCA risk groups, but argued that it was ‘impractical to extend the screening to the partners’ – despite the fact that University College Hospital did have partner screening for women with thalassaemia trait, considered to be found more commonly in Mediterranean families. Anionwu concluded that there was ‘an underlying racist and patronizing attitude that influenced the response of Authority members’, who had made assumptions that the black community were not educated enough to understand genetics and the high number of single black mothers would make it difficult to trace fathers. There was an insinuation that this group was promiscuous and lacked stable relationships simply because they were not married, revealing a

disturbing degree of ethnocentrism and failure to understand lifestyles different from their own white, male, middle class one.\textsuperscript{47}

These two objections – genetic understanding and uncertain paternity – were frequently cited by Health Authorities.

SCA was understood by the health service as an intrinsically foreign and tropical condition, which was inappropriate and wasteful to devote resources to in the white British population, conceptualised as an island nation. The question of where ‘immigrant populations’ resided in enough density to justify SCD screening programmes, and the discussions around the implementation of these screening programmes, reveals the paradoxical and contradictory approaches to ethnic minority health within the NHS. Broader political and sociological anxieties about migrants grouping together in ‘ghettoes’ and placing pressure on welfare services were countered by a rationalisation from healthcare professionals that, on the contrary, they weren’t grouped together enough for a cost-effective screening programme.\textsuperscript{48} Genetic screening programmes are a method of making the unseen seen – using accurate numbers of those living with the condition, services can be lobbied for and designed to meet need. Without these screening programmes, the true size of the SCD population was uncertain.\textsuperscript{49} Usha Prahar et al argued in 1985 that this uncertainty was of benefit to health authorities, because this ‘absence of statistics is in turn taken to represent the absence of individuals affected and used as an excuse for the failure to provide suitable facilities for screening and counselling’.\textsuperscript{50} After the implementation of a national screening programme for sickle cell and thalassaemia in 2005, the number of children identified with SCD dramatically increased, in some areas doubling the pre-existing workload. In assessing the results from the first two years of the screening programme, the programme team concluded that ‘[u]nderascertainment of the condition has allowed a downplaying of

\textsuperscript{47} Anionwu, ‘Health Education and Community Development for Sickl e Cell Disorders in Brent,’ 235-7.
\textsuperscript{49} A 1979 survey of SCD in Britain found 1300 cases treated in 12 months, but the authors admitted that the number could be double that. L R Davis et al, ‘Survey of Sickle-Cell Disease in England and Wales’, British Medical Journal 283 (1981): 1519–21.
\textsuperscript{50} Prahar et al, Sickle Cell Anaemia, 29.
the scale of need’ and may have factored into higher infant mortality rates in cities ‘as babies died without a diagnosis or treatment’. The invisibility of these patients hindered the case for interventions such as screening and counselling, and the limited data available on patient numbers also enabled the NHS to avoid accountability for these absent services.

**The development of local centres, 1979-1989**

From the early 1970s, officials, healthcare professionals, and black community workers began to advocate for a model of specialized centres to deal with haemoglobinopathies, located in areas with high ‘immigrant’ or ‘non-white’ populations. In September 1974, a BMJ editorial outlined a vision for future infrastructure to deal with SCD:

In the United Kingdom the first priority should be to establish hospital-based haemoglobinopathy clinics in areas with a large immigrant population. Each clinic would generate a nucleus of medical staff with specialist experience in the investigation and clinical management of haemoglobinopathies. The resulting co-ordinated service would raise the standard of supportive care for homozygous patients and would lead to increased awareness of the clinical complications of these disorders. Facilities for family investigations and for genetic counselling should also be provided, and the clinic would thus form a base on which to build future screening programmes.52

Black community health worker Jerry Crawford estimated in 1974 that there were 1,200 people with sickle cell disease and 60,000 with the trait in Britain. He recommended that also that ‘[c]ounselling units should be established in hospitals

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around the country to serve defined geographic areas'. Brent Sickle Cell and Thalassaemia Centre was established in Central Middlesex Hospital in 1979, and was Britain’s first specialized SCD centre. It was the brainchild of Elizabeth Nneka Anionwu, an Irish-Nigerian health visitor, and Milica Brozović, a haematologist who had migrated to Britain from Yugoslavia in 1964. The two women had independently become interested in the condition – Anionwu through her involvement with the black supplementary school movement, and Brozović through her encounters with patients on the wards at CMH. When Brozović and Anionwu met in 1976, at a lecture Brozović gave about pain control in SCD crises, ‘[w]e just clicked’, Brozović recalled. Their meeting sparked a ten-year collaboration. Brozović sought to address treatment, while Anionwu dealt with the social and educational aspects of the condition. Brent was an obvious candidate for a SCD centre – according to some sources it had the highest population of immigrants from the New Commonwealth and Pakistan (NCWP) in London. By 1985 the centre covered ‘an estimated Brent population of 36,000 Afro-Caribbeans, as well as people from adjacent districts’, and there were 193 recorded cases of sickle cell disease in the borough – increasing to 300 cases by 1987 and to over 400 by 1993.

The functions of the Brent Centre were varied. Anionwu described her role as providing ‘information, screening and counselling for inherited haemoglobin disorders’. A glimpse at her work during the first three months of 1980 reveals a varied workload – 14 home visits, 51 genetic counselling sessions, 11 ward visits (to liaise between patients and staff over issues such as pain management), and one bereavement counselling session. The centre was housed in the local Willesden Hospital, chosen because of easy access to blood tests but also because of its small

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54 DHSS documents refer to John Stuart of Birmingham (who had conducted the initial Birmingham screening pilots) as running a ‘sickling clinic’ in 1973, however the Brent centre was the first dedicated centre and space for SCD treatment. TNA BN13/41, ‘NBTS: Sickle cell anaemia’, Letter Henry Bunje to W Forbes, 3 July 1973.
57 Anionwu, ‘Health Education and Community Development for Sickle Cell Disorders in Brent,’ 103.
size and location within an at-risk community.\textsuperscript{59} As a result there were multiple referral pathways into the centre, with patients often by-passing appointments with general practitioners or haematologists: by 1987, over 50\% of the 3,000 people seen at the centre in its eight years of operation were self-referrals.\textsuperscript{60} In addition to its service function, the Brent Centre’s access to SCD patients provided opportunities for research into the symptoms, treatments and prognosis for the condition, aspects which had been historically neglected in Britain in favour of research into the molecular structure of haemoglobin.

Milica Brozović’s research output presented a picture of the SCD patient in Britain as prone to a different set of symptoms to those presented in the publications emerging from a Medical Research Council-funded unit in Jamaica, whilst also making arguments for a neonatal screening programme based on data from Jamaican and American studies. The role of ‘chest syndrome’ was observed in one publication as accounting for 21\% of patient admissions in Brent between 1962 and 1979, and in 1984 Brent paediatrician Sally Davies (who would become the Chief Medical Officer in 2010) and Brozović published an article demonstrating that these chest problems often described in SCD patients were likely often due to intravascular sickling rather than infection, and that exchange transfusion was therefore a more appropriate course of treatment than antibiotics.\textsuperscript{61} In other publications, they noted that leg ulcers were extremely uncommon in Britain but very common in Jamaica.\textsuperscript{62} Underpinning these publications, Brozović says, was a struggle between the London and Jamaican clinicians over the changeable nature of the condition and its link with geography.

Everybody said [chest syndrome was] a pneumonia, they put antibiotics into patients. It didn’t work because it wasn’t an infection, it was sickling in the lungs, and for years we could not get anybody to accept that the disease wasn’t the same in London as it was in Jamaica… the disease is affected by

\textsuperscript{59} Ibid, 103.
\textsuperscript{60} Ibid, 203.
geographical position… if you live in a cold damp climate… you are not going
to have leg ulcers, and you’re going to have chest problems and pain.⁶³

Brozović recalled that only when similar findings were published by hospitals in other large, industrial cities in the United States and France was a consensus established about the effect of geography upon SCD. This discussion tapped into a broader debate across the field about the impact of climate and seasonal change on the symptoms of the disease. Graham Serjeant observed in a 1976 ten year retrospective study that there was a close correlation between low temperatures and hospital admissions for severe painful crises of sickle cell disease.⁶⁴ Such research is reminiscent of nineteenth century race theories about climate and constitution, in which relocation to an environment dramatically different to a person’s ‘proper place’ (determined by assumptions about race and constitution) could cause degeneration.⁶⁵ In this context, these theories were framed as countering policymakers’ tendencies to generalize about SCD patients across continents and government complacency about the ameliorative effects of living in the NHS – making the argument that the British climate meant that effective heating and housing for SCD patients was of critical importance.

The staff at Central Middlesex Hospital further countered the complacency around SCD in Britain by arguing that prophylactic penicillin and pneumococcal vaccines should be routinely prescribed for babies. Such measures had been seen as unnecessary by NHS management, who considered some of the measures taken in Jamaica to be compensatory for what they saw as a less advanced healthcare system. ‘It was felt that such infections only happened in tropical rural Jamaica,’ Brozović remarked. ‘Not in a large city, in a developed country’.⁶⁶ Publications from both Brent and Camberwell made the case that ‘[i]t is a matter of utmost urgency that the British born babies with sickle cell disease are protected from the devastating

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⁶³ Milica Brozović, interview with author, 22 October 2018.
⁶⁶ Private communication, Milica Brozović, October 2018.
infections and high early mortality’, which they argued had been ‘successfully achieved in the USA and Jamaica through a programme of newborn screening, antibiotic prophylaxis, and parental education’. Anionwu and Brozović noted that the absence of early deaths in children between six months and three years old in their study when compared to childhood mortality in Jamaican SS patients ‘may well reflect a failure to recognise sickle-cell disease in early infancy… which could be rectified only by a programme of screening for sickle-cell disease in the neonatal period.’ Slowly, the Central Middlesex Hospital and the Brent Sickle Cell and Thalassaemia Centre and their associated staff, as well as other centres round the country, began to build an evidence base for SCD treatment – and the eventual national neonatal screening programme – in Britain. By 1989 the RCP stressed in their assessments of prenatal diagnosis for sickle cell that ‘Community-based screening is the ideal and is possible. Haemoglobinopathy centres… are a necessary resource for reaching the ethnic minorities.’ Elizabeth Anionwu herself became a member of the Nuffield Council of Bioethics Working Party on Genetic Screening in 1993. When screening for haemoglobinopathies was introduced to the National Screening Programme in the 2000 NHS plan, it was described as ‘an extension of services that were previously offered to individual families or members of particular ethnic groups’. The introduction of national screening thus built upon what had already been achieved by local services, using intelligence gathered and research conducted by local services.

The Brent centre became a blueprint for future sickle cell centres in Britain and was often the only centre referenced in service recommendations of the time. In 1988, the World Health Organisation referred to it in a report on haemoglobinopathies in Europe as ‘a model and a teaching resource for sickle-cell

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centres that are being set up in other parts of the country as a result of informed black community pressure. A year later, the Royal College of Physicians report pointed to the Brent centre as a hub providing training for haemoglobinopathy counsellors nationwide. After the establishment of the Brent centre, an Islington centre was established in 1982, run by health visitors already employed by the Local Health Authority, although by 1985 long-term funding had still not been obtained from the Authority. By 1985, London had centres in Brent, City & Hackney, Islington, Lambeth and Haringey. Elsewhere in England there were centres in Manchester and Liverpool. These centres had not been established as a result of DHSS or central NHS directives, but through the combined efforts of ‘departments of Haematology, Child Health and Community Medicine, individual health visitors, community health councils and community relations councils and the voluntary organisations’. The Manchester Sickle Cell Centre (MSCC) was established in 1984 after several years of campaigning from a local sickle cell support group, the Central Manchester Community Health Council and the Moss Side Family Advice Centre, as well as some interested local health professionals. Like the Brent Centre, it was considered essential by local organisers that the MSCC be based within the community rather than in Manchester Royal Infirmary. The MSCC was funded by the Regional Health Authority after the application of much pressure, other centres were funded by a combination of ‘Inner City Partnerships’, Community Unit Development Funds, or ‘Joint funding’. By 1991, at least twenty local services existed across the country. However, despite the British Society for Haematology’s 1988 recommendation that ‘[n]eonates from at-risk communities must be screened at birth for SCD… it may be necessary in some districts to screen all babies’, even boroughs with high percentages of at-risk

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74 Anionwu, ‘Health Education and Community Development for Sickle Cell Disorders in Brent,’ 201.
populations lacked such services. In 1991, a feature in the journal *Health Visitor* found that services continued to be variable even across London, the chief urban centre mentioned in policy reports. Wandsworth, with 27,000 African and Caribbean residents, had ‘the second highest proportion of Afro-Caribbean people of any London borough’ but no SCD centres, nor universal neonatal screening – unlike Brent, Hackney or Haringey, which all had lower proportions of African and Caribbean residency. Wandsworth health visitor Faye Harry remarked that ‘Dr Sherman at St George’s Hospital holds regular seminars on sickle cell, but for the life of her she can’t get any money to set up a sickle cell centre here’, which meant that families needing support and advice were forced to travel to a unit in Camberwell Health Authority.

A primary function of the centres was genetic counselling, in which couples could be tested and advised on their likelihood of conceiving a child with SCD. The success of counselling became implicitly tied to the ethnicity of the counsellors, which was seen as essential to avoid the dynamic of white doctors informing non-white patients that they had a genetic condition more prevalent in people of African ancestry. In 1989, the Royal College of Physicians emphasised the advantages of ethnic minority genetic counsellors in a report on best practice for prenatal diagnosis, advising that ‘the ideal specialist ethnic counsellors’ should ‘[belong] to an ethnic minority, but educated within the majority society, so that they can be a bridge for communication’. Such specialists would be able to speak with white doctors, but have links to community groups and information resources that non-minority personnel would have difficulty accessing.

A survey in 1996 of the ethnic origins of counsellors for sickle cell and thalassaemia, ‘[n]early 80 per cent (27) of all counsellors felt that ethnic origin was relevant to the post.’ Anionwu herself reflected that when she undertook her survey of parents of children with SCD in 1981, she felt she elicited her ‘very full and revealing responses’ because she was a

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78 Christina Potrykus, ‘Sickle cell: Call for better screening and universal services’, *Health Visitor*, 64, 12 (December 1991): 404-5.
80 Anionwu, ‘Ethnic origin of sickle and thalassaemia counsellors’, 183.
‘black health worker’ and also ‘visibly pregnant’.81 The specialised nurses and health visitors working in haemoglobinopathy units and SCD centres were commonly black women. However, because these units existed outside the traditional NHS structure, funded by short term grants and struggling to be incorporated into the NHS main programme, these women ‘risked their professional stability for this work’, often volunteering out of hours to ensure that the centres could run smoothly.82 This reflected a broader trend for black labour in the NHS. In 1968 Commonwealth migrants had made up 30 per cent of pupil nurse vacancies and 29 per cent of pupil midwives – but were also funnelled into the State Enrolled Nurse course rather than the State Registered Nurse course, barrng them from promotion and advancement.83 Though the local centre model for haemoglobinopathies was held up as an ideal framework for SCD treatment in which appropriate expertise could be generated, and though black healthcare workers were at the forefront of this work, the state’s inconsistent provision for ethnic minority health issues ensured that these centres also replicated the broader structural inequalities affecting black nurses. These centres, which worked to address the vacuum in state policy and medical research around the holistic, symptomatic treatment of individuals with SCD and to counter institutional racism within the NHS, did so even as their working conditions were shaped by state indifference to ethnic minority health.

Treating the crisis: Disbelieving and validating sickle cell pain on the ward, 1970s-1990s

Awareness of SCD among healthcare professionals was extremely poor during the 1970s and 1980s, and subsequently treatment standards varied dramatically. No national clinical standards existed for SCD until 2006 and textbooks were sparse.84

81 Anionwu, ‘Health Education and Community Development for Sickle Cell Disorders in Brent’, 179.
84 The standards and guidelines for care of SCD in childhood were launched in 2006 and for adults in 2008. Sickle Cell Society, Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK (London: Sickle Cell Society, 2008).
This lack of understanding among doctors and nurses about SCD, coupled with paternalist attitudes towards patients generally and stereotyped perceptions of black patients in particular, coalesced dangerously in the event of a sickle cell ‘crisis’. Vaso-occlusive sickle cell crises are caused by blood cells becoming hard and rigid, preventing their easy passage through veins, causing ischaemia and damage to tissue and organs, and disrupting blood flow in bone marrow. Patients commonly describe the pain as ‘excruciating’ and compared to the pain of a heart attack or cancer. It is the most common reason for SCD patient admission: between 1962 and 1979, 74% of all SCD patient admissions in Brent were due to painful crises. In 1980, a survey of nurses and health visitors in Brent and in Kensington, Chelsea & Westminster found that only 14% could identify analgesics for pain relief as one of the treatments for SCD. Aside from an MRI there is no way to confirm ischaemia, and so the central issue in encounters between healthcare professionals and patients in crisis is that of trust – the doctor or nurse doubting the extent of the patient’s pain, and the patient unable to trust in the doctor or nurse’s care. In the accounts of the healthcare professionals who pioneered SCD treatment in the 1980s and 1990s, their first encounters with SCD are often framed as encounters with a patient in crisis. The sickle cell crisis within the NHS clinic encapsulated for Milica Brozović and Elizabeth Anionwu the ill-informed and neglectful approach to SCD patients from NHS staff. Milica Brozović came to Central Middlesex Hospital hoping to conduct research on her particular area of interest – thrombosis. But, she recalled, it quickly became clear that thrombosis ‘was not the problem in Central Middlesex, the problem was sickle cell disease’. In her account, her realisation crystallised in a meeting with a SCD patient named Francis.

[H]e was lying by the bed, swearing, groaning, moaning, crying, making a terrible rumpus, they said, ‘This is your sickle cell disease patient, he’s a druggie, he is a malingerer, that’s what you have’. And then I, being who I am,

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talking too much, I went to talk to Francis, and discovered that he was absolutely desperate, hating everyone, because nobody believed him he was in pain, so once we gave him painkillers, rehydrated him, he became quite reasonable, and you know I started reading about it, because nobody seemed to know very much about it at that stage at least in Britain.

Brozović began reading the existing literature on SCD and to give lunchtime talks to nurses, ‘trying to get them to be more sympathetic towards the patients’ and explaining that ‘the pain was a very real thing’. She sought to show that SCD patients were not difficult, but in pain, and that it was important to have met the patient while not in crisis to understand the extent of that pain. Elizabeth Anionwu had a similar realisation. In 1976, she was working as a Community Nurse Tutor at Central Middlesex Hospital in north London. During a shift, a patient told her about a very young girl who was being neglected by the nurses. ‘She was under the bedclothes quietly sobbing her little heart out and had been in severe pain for many hours’, Anionwu recalled. ‘Immediately calling a nurse I made it clear that I would not leave until she administered an analgesic.’ The experiences of Brozović and Anionwu make it clear that sickle cell crises were highly charged encounters between healthcare professionals and patients which many perceived as indicative of a broader absence of care and responsibility for SCD patients within the NHS.

While many sources describe the proactive efforts of individual doctors to improve awareness of SCD and its treatment by healthcare professionals, of course few doctors or nurses have given accounts of their own ignorance of, or hostility to, the condition and its sufferers. This hostility only emerges from patient accounts or the observations of more sympathetic medical staff. During the 1980s, as voluntary organisations such as the Sickle Cell Society began to gather momentum, a series of patient surveys and policy documents articulated the existing experiences of ‘crisis’ in British hospital wards and framed them as a central issue. Within these surveys, similar experiences surfaced again and again: after the onset of pain, the person experiencing the crisis would try to ride it out at home, and would resort to hospital when the pain became unbearable. Upon arriving at A&E, they would wait to see a

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doctor, often for hours. A Brent sufferer recalled waiting four and a half hours without analgesia to see a doctor, and ‘constantly being told off for all the noise that I was making. I felt guilty enough without being told; I didn’t want to keep everyone awake. After about two hours I was moved to another bay to keep some other patients awake’. By morning, he had a temperature of 39.5 degrees centigrade and was, in his words, ‘delirious. Nothing else existed except the agony I was experiencing’. Helen* described her treatment in the 1980s as ‘a nightmare’ in which she was commanded to restrain her cries of pain, control herself. ‘There’s other people to consider, there’s other patients on this ward, you’re not the only patient,’ she recalled being told. ‘You’ve had a painkiller… if it hasn’t worked, then you know, you just want more painkillers’. Helen’s final sentence points to a common experience described by almost every patient I interviewed – the suspicion of the treating nurse or physician that the patient was a drug addict. Rob Boddice argues that within every social system or institution, ‘pain is only pain where it accords with tacit rules for the acceptable expression or experience of pain’. Here, the feedback from the nurses suggested that Helen’s expression of her pain transgressed these tacit rules within the hospital ward. Her pain was invisible, and therefore hard to verify. She was crying out, both asking for painkillers and moaning in pain, but she was expected to endure it in silence for the sake of other patients, implicitly reprimanded for selfishness, and suspected of drug-seeking. Suzanne*, who has SCD, was also a doctor who glimpsed this dynamic from the other side. During her haematology rotation in 1984, Suzanne often overheard ‘staff room talk’ about patients on the ward with SCD. ‘Some doctors were really caring’, she said, ‘but other doctors said ‘oh, they must be addicts. They’re just coming in for morphine, pain can’t be that bad.’

Joanna Bourke has demonstrated that anxiety that patients would become tolerant or addicted to analgesics was ‘the most important… reason medical personnel under-treated pain’ in the nineteenth and early twentieth centuries, and

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90 Helen (pseudonym), interview with author, August 2018.
92 Suzanne (pseudonym), interview with author, March 2018.
during the 1980s there was also considerable medical anxiety about the highly addictive painkiller pethidine, which was commonly used to treat sickle cell pain.\textsuperscript{93} Doctors expressed much concern about the sickle cell patients they encountered, who were often young people accustomed to high dosages of analgesics. Certainly pain relief for patients in hospitals could be generally poor: a 1977 survey in The London Hospital found that few patients were free of pain and many with malignant or terminal illnesses did not know their diagnoses.\textsuperscript{94} One doctor at a symposium about SCD pain relief in hospitals reflected that ‘when I had my gall bladder out and lay in a surgical ward for a few days it became apparent to me that both doctors and nurses are remarkably bad at treating acute pain, not just in sickle cell disease but post-operative pain and I think in other sorts of acute pain too’.\textsuperscript{95} But patients with sickle cell disease frequently reported nurses or doctors assuming them to be addicted to drugs, and their pain ascribed not to their biology but to social factors. Anionwu spoke to one patient who recalled that when the doctor arrived,

‘she started to call me a junkie and that I must face up to facts, that I don’t know my own mind. And when she left I became shaky, because what she said affected my nerves. I know to myself that I am not a junkie’.\textsuperscript{96}

Boddice argues that structures of racism can be enforced through conceptual notions of ‘emotional superiority’, in which the oppressor prescribes ‘emotional conformity, making for extremely strict emotional regimes that challenged those deemed racially inferior to meet almost impossible standards of emotional expression, given the often harsh or torturous conditions in which the emotives took place’.\textsuperscript{97} The tacit rule implicit in these encounters – ‘you’ve had a painkiller, if it hasn’t worked then you just want more painkillers’ and ‘they’re just coming in for

\textsuperscript{95} Dr Riordan, ‘Management of acute pain’, in \textit{Pain in sickle cell disease}, 29.
\textsuperscript{96} Sickle Cell Society, \textit{Pain in sickle cell disease}, 71.
\textsuperscript{97} Rob Boddice, \textit{The History of Emotions} (Manchester: Manchester University Press, 2018): 260.
morphine’ – meant that every effort to articulate pain was only read as further proof of drug-seeking.

Other symptoms of sickle cell also interacted negatively with a documented tendency among doctors at this time to pathologize black family life. Swollen limbs and joints are a common first symptom of sickle cell in infants, and two mothers reported to the Newham survey that when they brought their babies to casualty with this symptom, they were accused by the examining healthcare professional of child abuse. One of these mothers recalled

> The nursing sister said ‘What have you done?... What is wrong with him. I bet you’re not even married. What have you done to him? You can never trust anyone these days.’ I started crying, I couldn’t believe it. I felt the odd one out – the nursing Sister was accusing me of battering my child.\(^98\)

The mother’s sense of feeling ‘the odd one out’ speaks to the alienation that such treatment by healthcare professionals could produce. Historiographical considerations of post-war citizenship have discovered it to be fluid, in that ‘although non-white people may have had the status of formal citizens, they were not treated as such… restricting access to the basic necessities of life such as housing and employment’, or in this case, healthcare.\(^99\) When faced with an unknown condition with an unknown constellation of symptoms, it was apparently all too easy for stereotypes of drug addiction and dysfunctional family life to permeate medical diagnosis, permitting some health professionals to disregard the pain expressed by black people during consultation and attribute it to social rather than biological causes. This is consistent with what Ambalavaner Sivanandan, founder of the Institute of Race Relations, described as the ‘culturalism’ or ‘ethnicism’ of the British State under Thatcher.\(^100\) The situation with the mother accused of child abuse was only resolved when ‘[t]he mother eventually saw a black doctor passing by, and told him that she suspected her child had [sickle cell disease], and asked him to take a


\(^{99}\) Grant, ‘Historicizing citizenship in post-war Britain’, 1191.

blood test’. This speaks to the mother’s sense that the white healthcare professionals she encountered could not give her the benefit of the doubt, but also to how the encounter between the sickle cell patient and the refusing doctor could be mediated by a sympathetic third party.

When specialist SCD clinics, haematologists and nurses began to emerge in the late 1970s and early 1980s, they acted as intermediaries between patients, their treating physicians, and the broader edifice of the NHS – and a critical focus was legitimizing the pain of sickle cell crises. Lola Oni undertook work explicitly to educate healthcare professionals about sickle cell in her role as a health visitor at the Lambeth Sickle Cell and Thalassaemia Centre between 1985 and 1996. She delivered workshops and seminars, and ran case scenario group work across London hospitals, in order to improve understanding of the clinical standards and protocols needed to treat sickle cell disease. These sessions focused not just on clinical complexity and danger of sickle cell crises, but also attempted to create an empathic response to sickle cell patients in the medical personnel to whom she spoke. She recalled that the doctors and nurses they spoke to ‘were receptive to the education, but that didn’t change attitude. This is what we discovered – that despite all the education we did, and people understood, attitudes did not change’. She attributed this to the racist notion of young black people as ‘junkies’, and said the attitude of ‘utmost disdain’ from nurses was extremely difficult to shift. She also suggested that as the patients and the nurses were often the same age, the administration of pain relief was a form of power and control that some nurses enjoyed wielding. But Lola stressed that the key indicator for how a sickle cell patient would be treated in a ward was the attitude of the ward sister.

If you have a ward sister that believes that all sickle patients are junkies and a pain in the neck, you’ll find that most of the staff will feel that way too, because they will want to be accepted by the ward sister… [at KCH] we had a ward sister that was very – I’m not even sure it was it was racism or

wickedness... I couldn't understand why a lot of the staff were just so resistant to teaching, but when that ward sister left, the ward changed dramatically.\textsuperscript{102}

In this way, structure and authority within a hospital ward could enforce an emotional regime in which sickle cell pain could not be valid. Patients and interested doctors and nurses attempted to shift this attitude both through personal appeals for empathy and recognition, and through broader efforts to inform and educate, with varying degrees of success. Milica Brozovič also gave lectures and seminars to hospital staff on how to treat SCD crises, and found that when dealing with colleagues whose attitudes towards patients she considered to be unprofessional, leveraging her own emotions sometimes worked. ‘I discovered that if I cry, it’s very effective, because I did upset the English men when I cried’, she said. She described this tactic as her ‘work[ing] with’ her male colleagues’ expectations of her as an ‘emotional foreign lady’. By the mid-1980s, Brozovič said, she found her colleagues ‘were beginning to accept it, and to deal with patients the way I – we – thought was okay’.\textsuperscript{103} Through evoking the discomfort, pity or shame of her male colleagues through conscious emotional display, Brozovič felt that she was able to disrupt the emotional regime of hospital wards, and as a consultant haematologist she was in a better position to do so.

Suzanne said that she believed a turning point came in the 1990s, as a result of better awareness of the condition that was partly down to a fatal trial and error process. She recalled that during her work in the 1980s,

quite a few children with sickle cell anaemia, when they came into casualty, they arrested on the floor in the A&E waiting area and died… One family, she’d lost three children. And they’d all died in the A&E while waiting to be seen, because they had a massive pulmonary crisis, just keeled over. So they were beginning to realise, this is serious. Patients need to be fast-tracked, sorted out, people are dying.\textsuperscript{104}

\textsuperscript{102} Lola Oni, interview with GR, 10 April 2018.  
\textsuperscript{103} Milica Brozovič, interview with GR, 22 October 2018.  
\textsuperscript{104} Suzanne (pseudonym), interview with GR, 16 April 2018.
Lola Oni told me about the death of a fifteen-year-old girl as a result of a sickle cell crisis in Kings College Hospital during the 1980s, which she attributed to a mistaken belief on the part of the nurses that a sickle cell crisis could not be fatal.

she’d been calling out for the nurses, wanting pain relief because she was in so much pain, because sickle pain, you can’t see it… here’s a young girl, black young girl demanding opiates. Eventually she calmed down and the nurses were so grateful, ‘oh she’s gone to sleep, thank goodness’. And so they did the medicine round… she was very sleepy… They put the glass to her mouth. She took her medication, and they went away. A couple of hours later, they were doing the observation round, and she was dead. She’d had a bleed in her brain, that’s why she’d gone to sleep… the shock reverberated down the ward. The nurses were, there were tears.105

This girl’s pain had been invalid when she asked for pain relief because, as Lola observed, she was ‘a black young girl demanding opiates’. The shock of revelation that her pain had, after all, been extreme and her need for medical attention dire, could only come for these nurses not when she had lost consciousness but when she was found to be dead. The view that sickle cell patients were fundamentally malingers or drug addicts was so deeply and widely held, that the death of a child from the condition sent ‘shock reverberating down the ward’, and made the same nurses who had turned away from the child cry.

In 1987 Brozović and her colleagues argued in the *British Medical Journal* that it was ‘essential’ that guidelines for the management of crises, strokes, priapism and infections ‘are formulated, published and implemented along the lines of the Department of Health guidelines for haemophilia and the US guidelines for sickle cell disease’.106 In 1993, Sally Davies wrote an opinion piece urgently calling for research

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105 Lola Oni, interview with GR, 10 April 2018.
into pain relief for sickle cell crises.\textsuperscript{107} These pieces were deeply informed by their contact with patients at Central Middlesex. Where there had been almost nothing written about the experience of sickle cell, over the course of the 1980s the voices of patients and their families were elevated to the attention of policymakers by these publications. Eventually, this movement dovetailed with the reconfiguring of the patient-consumer by the Conservative government towards the end of the 1980s.\textsuperscript{108}

In 1990, the internal market was introduced, framed as the most effective way of delivering high quality care to individual patients. In 1993, the Department of Health launched a range of ‘Patient Perception Booklets’ aimed at purchasers to ‘help them with contracting for a high quality, patient responsive service’. One such booklet, authored by Anionwu, was entitled ‘Sickle Cell Disorder: Patient’s perceptions of coping with pain’. A briefing to Virginia Bottomley on the booklets noted that

\begin{quote}
We have made liberal use of patients’ quotations as a powerful means of illustrating what patients like – and dislike – about the service. Some of the quotes are critical of the service and make for uncomfortable reading. Professionals in particular may react to critical statements.\textsuperscript{109}
\end{quote}

The booklet pertaining to sickle cell pain contained quotations from patients articulating the emotional impact of delays in pain relief. ‘Every time I come to casualty they always seem to assume that I am a junkie desperate for drugs, which I find very insulting and depressing’, one quotation goes. In our interview, Lola Oni attributed the decline of overt racism in hospital wards to the move towards patient-centred care in the early 1990s. Today, she explained, ‘patient complaints exist, and patients can vote with their feet and go elsewhere, whereas in those days there weren’t many hospitals that had specialist care’. She suggests that the increased role of Patient Liaison Officers, patient organisations such as the Sickle Cell Society, broader awareness of SCD in hospital departments and the new value placed on

\textsuperscript{109} Karin Von Degenberg, ‘Patient Perception Booklets’, 18 October 1993, TNA JA418/7N/Z/1.
patient feedback from the 1990s onwards, meant that both poor treatment and racism from staff became increasingly less common within the NHS.

Conclusion

The reluctance of the National Health Service, and DHSS, to implement a national screening programme for haemoglobinopathies was not unusual. Internationally, post-war governments were reluctant to mandate genetic screening programmes. Moreover, screening and treatment was implemented in piecemeal form across many health conditions, from cervical cancer to tuberculosis, by Local Health Authorities during the period. Undoubtedly many with rare health conditions received inadequate attention from the health service, and many patients suffered under the paternalist, ‘doctor knows best’ attitudes of the 1960s and 1970s NHS. But while the poor treatment for SCD in much of the NHS was (in some ways) unexceptional for rare health conditions, this chapter has sought to show that the condition was racialized in ways that shaped the services that emerged around screening, diagnosis and treatment on the ground.

James Scott asserts that ‘legibility is a condition of manipulation’. The logic of state building says that societies need to be localized, stabilized and quantified in order for them to be of benefit to the state. By not collecting information on sickle cell disease in Britain – the state’s ‘way of seeing’ – multiple state actors across local and regional health districts during the 1970s and 1980s avoided accountability for sickle cell services. In declaring that there weren’t enough cases of sickle cell anaemia in some of the most diverse boroughs of the country, they minimized the existence of black communities which, in the same period, were closely watched by other branches of the British state, particularly the police. When advocates such

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as Brozović, Anionwu and Catherine sought to bring their superiors’ attention to the problem, they found the welfare state’s gaze was quickly redirected to rationalizations about the black community’s amenability to health intervention. Hospital consultants and local health authorities looked away from sickle cell disease, preferring to pathologize black families, and attribute sickle cell pain to social rather than biological factors. This failure to ‘see’ SCA was facilitated by central inaction and by a sense that it was a tropical rather than a domestic health concern. In this environment, health professionals made racist judgements about the black patients in their care with little consequence or accountability. Relationships between patients and doctors were charged, and hospital wards became sites of repressive emotional regimes in which black patients were disbelieved and left in agonising pain. In the context of post-war Britain ‘not seeing’ was as much a part of modern statecraft as ‘seeing’.

But this chapter has also shown how welfare state actors worked within NHS institutions to make sickle cell disease visible. They did so whilst incorporating the terms of legibility set down by the state. Despite their awareness of the deficiencies of selective screening, and its essentialization of sickle cell as a black disease, they initially undertook selective screening in order to appeal to the cost-efficiency agendas of Local Authorities and make the eventual case for the National Screening programme for SCD and Thalassaemia implemented in 2005. Sickle cell centres were funded by Inner City Partnerships, set up more or less to address ‘racial tensions’, but used this money to make the case for sickle cell anaemia to be incorporated into the mainstream NHS programme as a medical rather than a social issue. Expert workers attempted to counter medical complacency and shift the negative perceptions of SCD patients in British hospital wards, and to show the symptoms and associated pain of SCD as legitimate. This litigation over sickle cell between NHS workers sought to rectify the gap between the entitlements of Black Britons to state healthcare in principle, and the reality of a service unwilling to guarantee those rights. By making sickle cell a visible health issue in the language of public health, and compelling the state to see the people they were charged to care

for, these nurses, doctors and volunteers invoked the citizenship of Black British people, and presented an alternative vision of the welfare state. Nonetheless, the forms of SCD services that emerged in this period – selective screening and specialised local centres based in ‘multi-cultural’ areas – resulted from the condition’s total identification with ‘race’, ethnic minorities and the inner city.
Chapter 4: Between hospital and community: grassroots sickle cell activism, 1974-1997

Beginning in the mid-1970s, individuals and groups began to initiate grassroots action on SCD in England and Wales. Some groups were begun by healthcare professionals, others by patients. This chapter will assess how these groups connected the black radicalism of the ‘long 1970s’, African and Caribbean communities, the emergent patient movement of the 1970s and 1980s, and the NHS and the broader British welfare state. It will outline how these groups articulated the need for the symptomatic treatment of SCD, refocusing the discussion away from medical fascination with the genetic trait itself. In doing so, SCD advocates framed the condition as a potent symbol of the ‘uncaring arm’ of the British state and collaborated with sympathetic haematologists to create a foundation for evidence-based screening, counselling and management of the condition.1 In doing so, they made a claim for the equal treatment of Black British patients within hospitals and community care services of the welfare state. This chapter will focus primarily on the activities of two groups, the Organisation for Sickle Cell Anaemia Research (OSCAR), established in 1975, and the Sickle Cell Society (SCS), founded in 1979. It will draw upon the annual reports and newsletters of the Sickle Cell Society, oral history interviews with healthcare professionals Milica Brozovič and Lola Oni, and the memoirs of Neville Clare and Elizabeth Anionwu, two founding members of, respectively, OSCAR and SCS.

OSCAR and SCS are part of longer histories of protest against the treatment of Black and Asian people by the state. The methods of these protests varied from street protest and civil disobedience, to research and publications on the reality of racial discrimination in Britain, from legal challenges and submitting evidence to public inquiries, to the supplementary schools movement. As Kennetta Hammond Perry has demonstrated, organisations such as the leftist group Multi-Racial Britain, and the Campaign Against Racial Discrimination (CARD, established 1965),

challenged the limits of the 1965 Race Relations Bill through the submission of detailed evidence of police, housing and employment discrimination, ‘shatter[ing] the myth that racism was not an integral feature of everyday life in British society’.2 Throughout the 1970s, the West Indian Association and the Standing West Indian Conference published reports on police violence against black communities, and the latter submitted a report on police racism to a parliamentary select committee on race relations in 1972.3 In 1980-81, cities and towns across England saw uprisings from black communities, in response to the heavy-handed policing and discrimination they faced. Also in 1981, following the New Cross Fire in which 13 black teenagers died and its bungled investigation, 20,000 people marched from Deptford to Westminster in the Black People’s Day of Action.4 Throughout it all, the black radical press ‘enumerated the day-to-day encounters of black Britons with racism and exposed a world of police violence inconsistent with police and media accounts’.5 Historians have situated these actions within a wider transnational politics of black revolution, Pan-Africanism and Black Power, ideas which, like their proponents, criss-crossed between the United States, the Caribbean, Europe and decolonising African nations.6 A case study of SCD activism demonstrates that the articulation of the rights of black citizens also took place within the welfare state, countering institutional racism not in the form of restrictive immigration bills or police violence, but the more insidious and invisible discrimination of Local Health Authorities.

Sickle cell activist groups such as OSCAR and SCS had their roots not only in the crucible of black radicalism in the 1960s and 1970s, but also in the broader environment of health and consumer activism in this period. Hilton et al argue that medical advances saw the rise of condition-specific charities before the advent of the NHS – including the Imperial Cancer Research Fund (later Cancer Research UK,

1902) and the Asthma Research Council (later Asthma UK, in 1927). The post-war period saw the creation of many more such organisations, including the Haemophilia Society (founded in 1950), the blood cancer charity Bloodwise (1960), the British Heart Foundation (1961), Alzheimer’s Society and the Stillbirth Association (both 1979). A broader movement for patients’ rights also began in the 1960s, with the foundation of organisations such as the Patients’ Association in 1963, which sought to represent all patients in contact with the health services. These new ‘patient-consumer’ groups sometimes considered discrimination against ethnic minorities to be part of their remit – such as the social survey organisation Political and Economic Planning (PEP), connected to the organised consumer movement, which published a widely-cited study in 1967 showing that preference was given to white European migrants over non-white Commonwealth migrants in employment. PEP completed a series of studies in the mid-1970s demonstrating continued discrimination against ethnic minorities in British industry and manufacturing.

SCD activist groups incorporated anti-racist critique of the state and an articulation of black citizenship into these claims for patient rights. SCD activism therefore sat between two emergent rights discourses in the 1980s – a demand for the recognition of Black British citizens from black radical groups, and the articulation of the rights of patients from patient organisations. Indeed, the rights claimed by organisations such as the Patients’ Association ‘echoed the kinds of rights claims made by the new social movements of this period’ from the 1960s onwards. Their evaluation of the system linked these rights discourses to an analysis of who had power and influence within the bureaucracy of the state. They pointed out the whiteness of the architecture of state power – within NHS management, board rooms, and among politicians. They made these critiques from outside ‘radical’

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spheres, and though they critiqued the state they also sought redress and reform through the institutions of the state, and – like many other medical NGOs of this period – supplemented the welfare state. Simon Peplow’s work on the engagement of black communities with the inquiry into the St Paul’s uprising in 1980 argues that there was among these communities ‘a desire for increased participation within the British political system’, though he points to a division between ‘moderate’ groups of older black people and community workers who saw the inquiry as an opportunity to obtain resources, and younger black people more likely to be involved in the uprising who saw it as a distraction from the real issues and felt sceptical about any possible outcome. As the 1980s progressed, these organisations were also part of the ‘growing differential incorporation of Britain’s ethnic minorities into the structures of the state’ – which Waters and others have identified as a key factor in the decline of ‘political blackness’.

For several years both OSCAR and SCS received funds from the state through Section 11, Inner City Partnerships and the Greater London Council (see Chapter 2). OSCAR developed patient information materials for the NHS, while the Sickle Cell Society became deeply integrated with the specialist NHS sickle cell centre in Brent. At the same time, in their rhetoric, organisation, and framing of SCD, they were a patient-centred movement that sat both within and without the NHS, observing and critiquing the racist infrastructure of the British state. A study of the politics of SCD enables us to decentre black radical action in Britain away from its current historiographical locations – from CARD, CLR James’s drawing room, and the offices of Bogle-L’Ouverture to teenage girls in hospital beds, families in church, and black nurses in the community.

This chapter will first discuss the political origins of sickle cell advocacy in Britain by exploring the ‘political awakenings’ of two of its major figures, Elizabeth Anionwu and Neville Clare, and their engagement with discourses of Black Power, left-wing politics and the women’s movement in the 1960s and 1970s. It will then examine the rhetoric and advocacy of sickle cell activists, the political symbolism of SCD and its usage to isolate and identify institutional racism in the NHS, and the

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12 Waters, Thinking Black, 13.
fissions and fusions between the movement and conceptions of ‘political blackness’ and black radicalism in the 1980s. The second section will examine SCS and OSCAR’s engagement with black communities, mostly in London, in combating stigma, raising awareness, and empowering patients. In doing so, they made both SCD and state violence visible by publishing accounts and compilations of personal testimonies from patients and families living with SCD. The third section will explore the symbiotic relationship between SCS and the Brent Sickle Cell and Thalassaemia Centre and the broader welfare state during the 1980s and 1990s. They used methods from the playbooks of other voluntary condition-specific medical charities but faced challenges that others did not face. This chapter argues that sickle cell advocacy in this period combined the political philosophy of the British Black Power movement with the growing patient and condition-specific medical charities of the post-war period. These organisations articulated a forceful critique of an institutionally racist welfare state through their focus on sickle cell and brought the condition a new visibility – but their efforts were also frustrated by the economic disadvantages of black communities in this period.

Political blackness, Black Power and the politicisation of SCD in Britain, 1974-1987

Neville Clare and Elizabeth Anionwu, respectively the founders of OSCAR and SCS, explicitly linked their first encounters with SCD to their burgeoning engagement with transnational discourses of Black Power and black radicalism. Rob Waters argues that it was the ‘co-existence, indeed the bundling-together, of different historical temporalities that gave black radical politics in Britain the energy that it possessed, that drove its projects, that accounted for its appeal’ during the 1960s and 1970s. Histories of slavery and colonialism were animated within Britain’s black radical movement, Waters argues, and they ‘drove a new political formation, and offered new futures’. Anionwu and Clare, and the patients, parents, and healthcare

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13 Waters, Thinking Black, 220.
professionals who organised alongside them, incorporated past histories and present radical critiques of the British state into their understanding of SCD.

Elizabeth Nneka Anionwu was born Elizabeth Mary Furlong in July 1947, the child of a white Irish mother, Mary, who had had a love affair with a Nigerian student, Laurence Anionwu, while studying at Cambridge University. When she fell pregnant, Anionwu’s mother left university and returned home, and when Elizabeth was born she was taken to a Nazareth House by her grandparents. As a mixed-heritage child living between the Nazareth House and her mother’s home with her abusive stepfather, Anionwu experienced discomfort and abuse during her early life. In 1970, in her early twenties, she befriended a midwife from Benin while working in a neonatal clinic in Paris, who recommended Fanon’s 1952 book *Black Skin, White Masks* to her. Anionwu recalled that the book ‘abruptly woke me up to the realisation of my own sense of inferiority due to skin colour… I decided to stop straightening my hair. I was imbued with a quiet self-confidence, together with a keen desire to challenge racism whenever possible’. After training as a health visitor, Anionwu began attending meetings of the Socialist Medical Association and the radical Needle health group in the early 1970s, became Treasurer of her local Labour Party branch, volunteered for Ealing Commission for Racial Equality, and sold books for the black publishing house Bogle L’Ouverture at community events. Working as a health visitor in Wembley in 1971, Anionwu noticed that the Local Heath Authority was collecting ethnicity statistics (usually describing all non-white people as ‘New Commonwealth’) to gain Section 11 funds, and yet there were no interpreters to assist health visitors in communicating with non-English speakers. When she raised this with her superiors, she was threatened with failing her health visitors qualification. She went on a trip with the Fabian Society to New York where she visited the New York chapter of the Black Panther Party and met the civil rights campaigners Bayard Rustin and Marion Berry. In 1976, after reconnecting with her father, she took the name ‘Elizabeth Nneka Anionwu’ at the urging of her Nigerian

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16 Anionwu, *Mixed Blessings from a Cambridge Union*, 149.
Changing one’s name to reject the erasure of African identity was a practice in the United States and African countries that had been under colonial rule – Malcolm X chose ‘X’ to symbolise the true African family name he could never know in 1950, and in the same year that Anionwu changed her name, the Kenyan writer Ngũgĩ wa Thiong'o refused his given name, James, as ‘colonialist’.¹⁹

When Anionwu first heard the haematologist Milica Brozović give a lunchtime talk about SCD at Central Middlesex Hospital in 1976, she already had a ‘dormant interest’ in the condition dating from several years earlier, when she was involved in the Marcus Garvey supplementary school in Shepherd’s Bush, which ran on Sunday afternoons. When the founder of this supplementary school, Peter Moses, died of leukaemia ‘because he was young and black there was a rumour that he had died of sickle cell anaemia’, Anionwu later wrote. Several of his friends had heard of the illness through their black activist contacts in the US, where the condition ‘was experiencing unprecedented media and political attention’. Anionwu, as a nurse, attempted to explain the difference between the two conditions but was embarrassed to find she knew very little about SCD. Her ‘close friend’, radical Black publisher Jessica Huntley,

forcibly pointed out to me, that as a black health worker, I should have been the person to whom the others could turn to for information about an illness that affects the black community. This encounter is a useful example of the influences that can occur within a particular social network, in this case the black community.²⁰

She had also come across several patients with SCD in the course of her work as a health visitor. These encounters, through both her profession and her involvement in radical Black activism, ‘were to play on my mind constantly’ until her meeting with Milica Brozović. This meeting was no less significant for Brozović, who saw

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¹⁸ Ibid, 191, 203.
²⁰ Elizabeth Anionwu, ‘Community development approaches to sickle cell anaemia’, 10 March 1988, Private collection.
Anionwu’s strong links into both the nursing community and the black voluntary community as crucial to their shared mission to improve care for patients.\textsuperscript{21} Together, they planned a ‘two-pronged’ approach, ‘educating health professionals as well as providing support for patients and families’.\textsuperscript{22}

Anionwu began her work with SCD at the same time as she became involved with Organisation of Women of African and Asian Descent (OWAAD) and the Moss Side Black Women’s Cooperative, whilst undertaking a Masters at Manchester University.\textsuperscript{23} Stella Dadzie of OWAAD recalled Anionwu had been partly responsible for bringing the group’s attention to the issue of SCA, a subject that her local group ‘took up’. In an oral history interview, Dadzie articulated her understanding of the campaign as one that was centred on raising awareness among the medical profession, ‘which in most mainstream hospitals didn’t even have a name’. Dadzie understood SCD to bring up ‘lots of issues that were for women’ due to its implications for reproductive choice and care for sick children.\textsuperscript{24} OWAAD member Judith Lockhart recalled that SCD was one of an interconnected set of issues that were of key importance to Black women’s groups at the time: that of health and welfare. SCD, like domestic violence and advice from health professionals and institutions around contraception, was understood by these groups to stem from an NHS and wider Welfare State that was at best deaf to, and at worst prejudiced against, the health and social care needs of Black women. The issue of SCA was raised by the National Black Women’s Conference and OWAAD.\textsuperscript{25} \textit{The Heart of the Race}, written by Dadzie with Beverley Bryan and Suzanne Scafe, devoted a chapter to ‘The Uncaring Arm of the State’. They argued that though the health service is ‘both directed and controlled by white, middle-class men’, as women, they could not avoid encountering it. ‘It is us who bear the brunt of the responsibility for our own and our families’ health… quite apart from our many specific health needs as women’, and it was for this reason that Black women were so ‘vital’ to campaigns around

\textsuperscript{21} Anionwu, \textit{Mixed Blessings from a Cambridge Union}, 244.
\textsuperscript{22} Ibid, 247.
\textsuperscript{23} Ibid, 209.
\textsuperscript{25} ‘National Black Women’s Conference 18 March 1979 – Introductory speech’, DADZIE 1/1/14, Black Cultural Archives.
health issues.\textsuperscript{26} The majority of those involved with the management of the Sickle Cell Society from its inception were women. Between 1982 and 1991, SCS committee membership was 82\% female on average, and in the 1988-89 committee 11 out of 12 committee members were women (see Table 1).\textsuperscript{27} In 1985 the North and East Branch of the Sickle Cell Society elected four women to its five-person committee, and noted in the SCS annual report that over half were parents, saying ‘[w]e feel confident that they can guide the Group as to the best way forward in catering for the needs of sickle cell sufferers’.\textsuperscript{28} Anionwu noted the dominance of women in the organisation in an interview in 1983, observing that in her experience women ‘cope more with the illness’:

\begin{quote}
Amongst our group, off-hand, I can think of more women who are working, studying, bringing up families, despite the illness and appear fairly well ‘adjusted’ to the fact they have a chronic illness. Whereas men don’t appear to have adapted as well.\textsuperscript{29}
\end{quote}

\begin{table}
\centering
\caption{Sickle Cell Society Committee gender breakdown 1982-1998}
\begin{tabular}{|l|c|c|c|}
\hline
Year & No. women members & Total committee membership & \% women \\
\hline
1982-83 & 10 & 12 & 83 \\
1983-84 & 6 & 9 & 66 \\
1984-85 & 9 & 12 & 75 \\
1985-86 & 11 & 12 & 91 \\
1986-87 & 9 & 12 & 75 \\
1988-89 & 11 & 12 & 91 \\
1990-91 & 10 & 11 & 90 \\
1992-93 & 9 & 12 & 75 \\
1995-96 & 6 & 11 & 54 \\
1997-98 & 5 & 9 & 55 \\
\hline
\end{tabular}
\end{table}

\textsuperscript{26} Bryan et al, \textit{The Heart of the Race}, 90.
\textsuperscript{27} Table 1 references collated from the Annual Reports of the Sickle Cell Society.
\textsuperscript{28} Sickle Cell Society, ‘Annual Report: 1985-6’, SCS.
\textsuperscript{29} Dorothea Smartt, ‘Sickle Cell Anaemia Women speak out’, \textit{Spare Rib} 126 (June 1983): 22.
The struggle of black women in the health service was in ‘individual battles with GPs, health workers or hospital consultants’ as well as in collective action – and the issue that Bryan, Dadzie and Scafe used to demonstrate this collective action was in sickle cell. ‘Black women have taken the initiative not only to inform our own communities about the facts of Sickle Cell, but also to raise funds and resources to sponsor the urgently needed research’, both within OSCAR and in wider Black women’s and community groups across the country. However the dissolution of OWAAD in 1982 prevented the group’s long term involvement, and radical black women’s groups were rarely involved in the details of the SCA campaign. Dadzie reflected that because much of the necessary work was internal to the National Health Service, educating healthcare professionals on the condition, the cause did not require ‘on the floor campaigners in that sense’. The SCD struggle took place in GP surgeries, accident and emergency rooms and haematology wards, rather than through protest. Only those involved in the day-to-day work of SCD – patients, parents, nurses and doctors – were in a position to meaningfully address the issues in its treatment. The comparatively loose connections between groups such as OWAAD and the Brixton Black Women’s Group (BBWG) and sickle cell advocate groups, despite the significance of women to the latter, may also have been the appeal of SCD as a practically-focused, single issue campaign. In her oral history research into race and ethnicity in the women’s movement, Natalie Thomlinson interviewed the black youth worker Yvonne Field who felt ‘more comfortable with practically-focused activism that was still progressive but less overtly political’. SCD also surfaced within the broader women’s liberation movement, and Spare Rib published an article on the condition in 1983. Spare Rib was framed as representing the whole WLM movement, and it was during the 1980s that the publication was challenged about its representativeness both in terms of content and its editorial

team, particularly along the lines of race, class and sexuality.\textsuperscript{33} In 1983, the British-Barbadian poet Dorothea Smartt covered SCD from a women’s perspective for \textit{Spare Rib}. In her interview with the patient ‘J’ she covered the intersection of race and gender, asking ‘Do you think if you were a Black man things would have been different?’ in respect to J’s experiences with pain relief in hospital.\textsuperscript{34} As the broader women’s movement struggled to reckon with the intersections of race and gender, SCD was an issue they sometimes reached for to signify their engagement with the struggles of their black sisters.

Despite the dominance of women in the SCD community, it was a man – Neville Clare – who founded OSCAR, the first SCD organisation in Britain. Clare was born in 1946 in Kingston, Jamaica, and moved to Britain aged eleven. He inherited a variation of SCD, sickle cell-haemoglobin C disease. Living with unknown aches and pains since childhood, he suffered several sickle cell crises before he was belatedly informed of his diagnosis by a nurse in 1967.\textsuperscript{35} As a young professional draughtsman in 1960s London, Clare frequented the West Indian Student Centre in Earl’s Court, a frequent haunt of both British activists and African American intellectuals such as James Baldwin, who gave a speech there in 1968.\textsuperscript{36} Enthused, Clare formed a small organization called the Council for Afro-Asian Peoples (CAAP) with several friends in the same year. He recalled one instance in which he and several friends showed a London Underground ticket inspector their Malcolm X posters with the slogan ‘by any means necessary’ instead of their tickets, and like many in the student movement endorsed the radicalism of Black Power over the middle way of Martin Luther King.\textsuperscript{37} He and a friend attempted to set up a business in the early 1970s – a bank named Monopoli which provided mortgages and loans for the black community. This, an article in the newspaper \textit{West Indian World} reported, arose because '[Clare] thought about the underprivileged [sic] in the community who were getting absolutely nowhere by demonstrating. Neville thought

\begin{itemize}
\item \textsuperscript{33} Ibid, 27.
\item \textsuperscript{34} Smartt, ‘Sickle cell anaemia’, 20.
\item \textsuperscript{35} Neville Clare, \textit{An OSCAR for my troubles: A Life Working for Better Understanding and Treatment of Sickle Cell Disorder} (Oxfordshire: Neville Clare in conjunction with Writersworld Ltd, 2007): 42-3.
\item \textsuperscript{36} Waters, \textit{Thinking Black}, 12.
\item \textsuperscript{37} Clare, \textit{An OSCAR for my troubles}, 46.
\end{itemize}
that if they had economic stability it would be one way of getting there’.\textsuperscript{38} It was through this engagement with histories of blackness and with black self-help initiatives that Clare parsed his understanding of SCD.

Clare recalled his ‘painful realisation’ of the reality of slavery in the lives of his ancestors and the history of his country, and recalled that ‘[n]ot least of the dehumanising aspects of the system was the destruction of traceable lines of genealogy’, as families were separated from each other and sold, casting their ‘previous names and tribal identity’ into obscurity. But, Clare said, he did know some things about his ancestors:

\begin{quote}
[I]long ago, some of them lived in [an area where] one of the most serious forms of malaria, falciparum malaria, was prevalent: probably West Africa or an area south of the Sahara and north of the Zambezi. In the distant past, there was a struggle for survival as people tried to penetrate and settle those areas’, and eventually ‘a few of my ancestors acquired a gene that helped to ensure they had descendants, they survived the ravages of malaria.\textsuperscript{39}
\end{quote}

For Clare, the painful lived experience of sickle cell-haemoglobin C also had the potential to re-establish the lines of genealogy that forced migration and slavery had ruptured. At the same time, he understood the lack of education and awareness around SCD to be tied to the continuing disenfranchisement and discrimination against black people in Britain and the United States. After his diagnosis in the late 1960s, Clare had looked in London for information about his condition to no avail.\textsuperscript{40} Ultimately it was \textit{Sickle Cell Disease: Diagnosis, Management, Education and Research} – a collection of papers from a conference in New York in 1971 – that he dubbed his ‘bible’, and armed with it he began to conceive of establishing an organization for SCA. Clare incorporated his burgeoning knowledge of SCD into an understanding of his origins, and his early efforts to begin a sickle cell organisation coincided with Alex Haley’s 1976 book \textit{Roots: The Saga of an American Family} and

\begin{footnotes}
\footnotetext[38]{‘Business Leaders’, \textit{West Indian World} (January 18 – January 24 1972): 5.}
\footnotetext[39]{Clare, \textit{An OSCAR for my troubles}, 73-4.}
\footnotetext[40]{Clare, \textit{An OSCAR for my troubles}, 53.}
\end{footnotes}
the television series of the same name from the following year, which was widely credited with stimulating an interest in black genealogy across the African diaspora.41

Clare turned to his American reading materials and began to telephone the grassroots organisations he saw listed there: the Sickle Cell Disease Foundation of New York and the National Association for Sickle Cell Disease among others. He gauged that their chief purposes were awareness-raising, but also ‘began to pick up from the way they spoke on the phone that at that time sickle cell in America was not seen just as a health issue but as a major political issue’, articulated as a critique of American government inaction and neglect, compared with the (lesser) frequency and (greater) funding for genetic illnesses affecting white Americans such as cystic fibrosis, and framed at times as a silent ‘genocide’. Clare was also ‘inspir[ed]… to learn that figures in the American civil rights and black power movements [sic] whom I had revered, such as Malcolm X, Stokely Carmichael and H. Rap Brown, had long been active in the cause of sickle cell’, and had not been ‘embarrassed or ashamed or hesitant for any reason’ to speak about the illness.42

During their short working partnership, Anionwu and Clare together undertook a trip to the United States. While Clare researched in New York, Anionwu visited centres in Los Angeles, San Francisco and Oakland.43 There she observed the impact of the notorious 1972 National Sickle Cell Control Act, which had meant that 15 comprehensive centres for care, research and screening had been established in the USA by the mid-1970s.44 At the San Francisco centre, Anionwu recalled meeting Sylvia Lee, a sickle cell nurse whose ‘philosophy of care influenced me immensely… It gave me the idea that once back in Brent, I too could deliver a similar service’.45 The American legislation arose out of a mixture of lobbying by sickle cell groups and the Black Panther Party, who themselves established clinics which distributed information leaflets about SCD and its inheritance, and in which people could be

42 Clare, An OSCAR for my troubles, 78-80.
43 Clare, An OSCAR for my troubles, 122.
45 Anionwu, Mixed Blessings from a Cambridge Union, 252.
tested for the sickle cell trait. Thus the Brent centre had its origins partly in the US Black Power movement, which had been very influential on the framework of black politics more broadly. Visits to the UK by Malcolm X in 1964 and 1965, by Stokely Carmichael in 1967, and James Baldwin in 1968, as well as reports of the United States Black Panthers on British television, had exposed US Black Power to a British audience, and generated a British Black Panther Movement from around 1968 to 1973. In August 1970, Black Panther banners and chants were seen at the Mangrove protest march and the subsequent trial of the Mangrove Nine, described by Waters as ‘the high-water mark of Black Power in Britain’.46 The example of SCD illustrates the deep influence of Black Power rhetoric and frameworks in Britain’s welfare state as well as its radical politics of protest into the 1980s.

While transnational black radicalism influenced Anionwu and Clare’s sickle cell activism, and shaped the way they made sense of the disease’s neglect by the British state, those working in the broader field of ethnic minority health sometimes saw SCD activism as a distraction. In 1983, one Dr SP Sashidharan, a Scottish psychiatrist, expressed his frustration in the Marxist pamphlet Radical Community Medicine that sickle cell disease was such a focus of black health workers. ‘We must move away from ‘specific conditions’ to those which are relevant to the vast majority of black people in terms of disadvantage and discrimination,’ Sashidharan argued, and ‘focus attention on, say, bad housing, unemployment, high infant mortality as reflections of the way racism operates in mediating illness and suffering’.47 OWAAD members Beverley Bryan, Stella Dadzie and Suzanne Scafe, in The Heart of the Race, reflected on NHS ignorance and neglect of SCA and the ‘collective response’ to articulating it as a health issue – but quickly reflected that ‘the availability of State funding and the growth of the ethnic industry’ had led to the emergence of black health experts – often black women. ‘Although the role of such experts remains potentially progressive,’ they reflected, ‘the dangers of ghettoising Black health

concerns within the NHS cannot be ignored... the fundamental problem of racism remains largely unchallenged.\textsuperscript{48} This line of thinking held that genetic conditions such as SCA let the government off the hook, and were a distraction from the broader health impacts of structural racism.

Others understood SCA as a useful case study to trace the indifference of the NHS to the health of black communities. The black health activist Allan McNaught contended in 1987 that although SCD was not the primary health concern of ethnic minorities, ‘[t]he specific importance of these two conditions (sickle cell and thalassaemia) is that they provide us with useful bench-marks to assess the willingness and ability of the NHS to respond to the specific needs of ethnic minorities’.\textsuperscript{49} The black community health worker Protasia Torkington used the case study of SCD, which she calls ‘a specific condition virtually exclusive to black people’ in her 1985 PhD thesis to illustrate the broader issues of racism in the NHS. In her study, examining the healthcare provision for the black communities of Liverpool, Torkington argued that

The case of sickle cell disease demonstrates clearly the effect of racism which is reflected by the neglect shown in a health need specific to the black population. In rickets, infant mortality and mental health the analysis by the experts have tended to obscure the practical reality of racism in the field of health. But in sickle cell without the cultural factors to obscure the picture, the effects of racism have been thrown into sharp relief. Although sickle-cell [sic] is important in the lives of many black people, this should not blind us to the realisation of the political causes of ill-health which affect the whole of the working class population of which black people are a part.\textsuperscript{50}

In characterising SCD as an illness ‘virtually exclusive to black people’, advocates used it as a means to draw out, isolate and analyse the presence and effects of

racism in the NHS. The provision for SCA and thalassaemia could be assessed alongside the provision for comparable health conditions for northern Europeans, and any disparities could then be imputed to treatment for ethnic minorities within the health service as a whole. In 1995, Lola Oni delivered the 8th Annual Martin Luther King Memorial Lecture at the Lambeth Mission, as part of a group ‘whose aim is to encourage and promote activities to educate and strengthen the Black community’. In her lecture, titled ‘Black Holes in a White NHS’, she asked ‘Does the national health service provide an equitable service to us its Black citizens, according to our specific health needs?’ She used SCD as an example to illustrate her argument that ‘those holes are us, the Black community, and other vulnerable members of society. By virtue of our exclusion from health management boards and executive councils’.51

The comparison between provision for SCD on one hand, and cystic fibrosis and haemophilia on the other, was a consistent theme in discourse around SCD activism. The doctor Gerry Dawson threw down the gauntlet in a Race Today article in 1974, arguing that ‘If the children of company directors and MPs and disc jockeys died horribly of sickle cell anaemia, it would be a more popular cause than polio and cystic fibrosis research funds put together, and black people themselves would at least be more aware of the risks they face.’ 52 Dorothea Smartt’s first question to the SCD patient ‘J’ in her 1983 Spare Rib piece was ‘Do you think that if white people suffered, the profession would know more about it?’, to which ‘J’ answered, ‘Yeah! That’s true that if white people got it as well it’d be taken a lot more seriously’.53 In November 1985, SCS, OSCAR and representatives from SCD centres organized a parliamentary event at the House of Commons. 60 individuals attended but were met by three MPs out of 100 who were contacted by the group because of their stated interest in ‘race issues’. At this meeting, Milica Brozović informed the assembled group that DHSS had authorized £15 million for the haemophilia treatment Factor 8, while it had divided £26,000 between the Sickle Cell Society and OSCAR.54

How did the question of SCD fit into the broad conception of ‘political blackness’ and radical black politics in the 1970s and 1980s? Stuart Hall argued that successive Immigration Bills restricting British citizenship, the introduction of Race Relations legislation, and the rise of Powellism following Enoch Powell’s ‘rivers of blood’ speech meant that between 1962 and the mid-1980s, race – particularly the division between white and non-white – became ‘the prism through which the British people [were] called upon to live through, then to understand, and then to deal with the growing crisis’.55 The political concept of ‘blackness’ for a time allied people of African and Caribbean heritage alongside British Asians. Incorporating critiques of imperialism, slavery and postcolonial racism, as well as cultural forms and practices from South Asia and the African diaspora, blackness was an ‘unstable, often contradictory, coalition’ that was nonetheless ‘coordinated to considerable political effect’.56 SCD presented both an opportunity and a problem for this formation of blackness, for it was loosely defined by activists as ‘a particular kind of critical perspective informed by the experience of racialization, and the politics that this entailed’, and so ‘blackness did not coincide neatly with any biological fact or supposed ethnic group’.57 Where did sickle cell, as a ‘biological’ disease found more commonly among certain ethnic minorities, fit with this concept?

The research of Hermann Lehmann and his colleagues (see Chapter 1) into the sickle cell trait and its allied conditions had found sickle cell varied in frequency across Africa, but could also be found in India and the Mediterranean in high frequencies. These haemoglobinopathies, including thalassaemia (common in the Mediterranean, the Middle East and south Asia) affected groups of peoples that, in Britain, were often first or second generation migrant communities and racialized to a greater or lesser degree. Moreover, these genetic traits interacted with one another. If an individual had a copy both of the sickle cell trait and the thalassaemia trait, then they were affected by the illness sickle cell thalassaemia, and if an individual had a copy each of sickle cell and ‘haemoglobin C’, they had a somewhat less severe condition known as sickle cell-haemoglobin C. Neville Clare reflected that

55 Stuart Hall quoted in Waters, Thinking Black, 5.
56 Waters, Thinking Black, 8.
57 Ibid, 4.
[l]earning about sickle cell disorder in fact forces you to think about what is meant by colour and race. Skin colour in scientific terms is not a very clear or precise indicator of parentage or racial background; it varies very readily and can change rapidly in the space of very few generations.

He noted, however, that this was rarely understood about SCD and thalassaemia, which ‘continue to be defined (especially when spending priorities are discussed) as only affecting a minority, rather than the “general population” – as if this is not a definition that can apply to any illness; that it affects only those who are affected by it’. In this way sickle cell and thalassaemia were an adept expression of political blackness – funding allocation for the conditions was informed by their racialization as ‘minority’ conditions, even as they ‘did not coincide neatly with any biological fact or supposed ethnic group’. In their publicity materials, both OSCAR and SCS frequently debunked the conception of SCD as a ‘black disease’. An early front page piece in *West Indian World* by OSCAR in 1977 also mentioned that ‘Mediterranean people’ could carry thalassaemia, and a follow up piece was careful to emphasise the link to malaria as the reason for its distribution. Anionwu, describing her frequent media enquiries about SCA, cited the question ‘is it true that only black people get it?’ which she editorialised with an immediate ‘(No!)’.

Short explanations of SCD were commonplace to most articles and pamphlets on the condition, and always included a line referencing its distribution in certain ethnic communities. In one 1985 paper, Anionwu explained that

About 1 in 200 babies born to Afro-Caribbeans and 1 in 100 born to West Africans have sickle cell disorders. However it is not just confined to this section of the black community as is often stated.

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59 ‘Sickle Cell Anaemia – The Unknown Killer Disease’, *West Indian World* (Friday, March 25th to Thursday, March 31st, 1977): 1; ‘What is Sickle Cell Anaemia?’, *West Indian World* (Friday, April 1st to Thursday, April 7th, 1977): 4.
61 Elizabeth Anionwu, ‘Community development approaches to sickle cell anaemia’, 10 March 1988, Private collection.
In this, the late 1980s, the broader definition of ‘black’ as including ‘Asians, Eastern Mediterraneans and Arabs’ (as Anionwu goes on to explain) was clearly still in use.\textsuperscript{62} A 1992 pamphlet outlined the affected groups as ‘mainly… people of African or Caribbean origin’, but also mentioned ‘people from the Mediterranean, Asia and the Middle East’ as risk groups.\textsuperscript{63} Thus the sickle cell trait itself, alongside the thalassaemia trait, was congruous for a long period with the conceptions of political blackness. But despite this, the voluntary organisations were separated into ‘sickle cell’ and ‘thalassaemia’, for despite their commonalities there were many differences between the conditions. The issue of painful crises – a central animating issue for individuals with sickle cell – was not found in individuals with thalassaemia. Finally, how healthcare professionals conceived of the family structures in Greek, Cypriot, Indian and Pakistani communities, compared with how healthcare professionals understood African and Caribbean family structures, was also different and of crucial importance to discussions about genetic screening and counselling. It was considered desirable that the ethnicity of genetic counsellors matched the ethnicity of the target population. The UK Thalassaemia Society itself, established 1976, had had a primarily Greek and Cypriot leadership and membership, and it was only in the mid-1980s that they began to release information leaflets in the five main Asian languages and to widen its base.\textsuperscript{64} Their first Asian President, Mahesh Kotecha, was elected in 1985.\textsuperscript{65} Therefore, the national sickle cell organisations cooperated with, but were distinctly separate from, the UK Thalassaemia Society. On a local level there were exceptions, such as the Wellingborough Sickle Cell and Thalassaemia Support Group, founded in 1988.\textsuperscript{66}

However, while this division between sickle cell and thalassaemia existed on the voluntary level, sickle cell and thalassaemia were often grouped together within medical centres, often because haematologists treating SCD had thalassaemia

\textsuperscript{62} Ibid.


\textsuperscript{66} Sickle Cell Society, ‘Newsletter No.33’ (November 1988), SCS.
within their remit. The Brent Sickle Cell and Thalassaemia Centre, the George Marsh Sickle Cell and Thalassaemia Centre in Haringey, and the South Glamorgan Sickle Cell and Thalassaemia Project in Wales, were all set up by haematologists, counsellors and volunteers and sought to address both conditions. After leaving CMH in 1990, Anionwu became a Lecturer in Community Genetic Counselling at the University of London Institute of Child Health, where she developed a course for healthcare professionals on a ‘multi-ethnic’ approach to community screening, addressing SCA, thalassaemia, Tay-Sachs and cystic fibrosis. The philosophy of this course addressed the ‘classic misunderstanding’ that these conditions were limited to, respectively, the black community, Greeks and Cypriots, Ashkanazi Jews, and white Europeans. ‘Less well known was that all of these conditions are also seen in other groups, although usually to a lesser extent’, Anionwu wrote. ‘Between them, all these genetic disorders impact on most communities in this country’. At the central state level, too, the voluntary groups were encouraged to collaborate and integrate rather differentiate along ethnic lines. In 1988, DH under Edwina Currie as the Public Health Secretary coordinated a series of consultations with haematologists, counsellors, UKTS, OSCAR and SCS to produce haemoglobinopathy cards to be presented to individuals following screening. Buoyed by this success, Currie organized a series of meetings with the UK Thalassaemia Society and some ‘sickle cell groups’ which presumably included OSCAR and SCS, to propose ‘a national organization to co-ordinate the efforts of the voluntary bodies concerned with haemoglobinopathies’. UKTS, OSCAR and SCS all raised concerns about ‘lo[sing] their identity’ in such an arrangement, and the plan never came to fruition.

By the time OSCAR, SCS and UKTS were gaining momentum in the mid-1980s, the conception of political blackness had begun to fracture. By this point, Waters argues, the ‘growing differential incorporation of Britain’s ethnic minorities into the structures of the state’ – a key factor in the decline of radical blackness – was well underway. As the cause of SCD was inevitably focused towards

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68 Sickle Cell Society, ‘Newsletter No.32’ (May 1988), SCS.
incorporation into the state, through several key milestones such as the inclusion of SCD in the NHS main programme funding and the National Screening Programme, SCA activism would surely be particularly prone to this differential incorporation.

From its earliest days, OSCAR collaborated with the Commission for Racial Equality to produce information leaflets.\(^71\) The first meeting of Brent OSCAR in autumn 1977 was held in the local office of the Community Relations Council.\(^72\) These institutions were part of the ‘growing movement within the state in the 1980s to accommodate black political and cultural initiatives’, exemplified in the Racism Awareness Training of local councils, black ‘self-help’ initiatives funded by Inner City Partnerships, and the Labour Party Black Sections movement.\(^73\) Indeed, Diane Abbott and Paul Boateng – two of the four black and Asian MPs elected in 1987, an event hailed as the crowning achievement of Black Sections – were both deeply involved in the work of SCS.\(^74\) Paul Boateng was a regular fixture on the sickle cell fundraising circuit, frequently pictured at the annual Jeff Johnson memorial bicycle race, while Diane Abbott set up and chaired the All-Party Parliamentary Group on Sickle Cell and Thalassaemia.

The SCD movement arose from a particular moment in Black British politics – creating external welfare structures in a manner borrowed from the supplementary schools movement, to a popular fascination with ancestors and lost histories of the Black Diaspora encapsulated in *Roots*, and the influence of US Black Power and their SCD movement across the Atlantic – these influences can be seen in the inspiration and development of OSCAR and SCS.

**Sickle cell activism in black communities and families**

In early 1979, OSCAR, led by Neville Clare, and the Brent branch, led by Elizabeth Anionwu and Sherlene Rudder, parted ways. Anionwu’s account of the schism in her memoir holds that this was caused by the success of the Brent support group. Brent

\(^71\) Clare, *An OSCAR for my troubles*, 105.
\(^72\) Clare, *An OSCAR for my troubles*, 106.
\(^73\) Waters, *Thinking Black*, 215.
\(^74\) Marc Wadsworth, a founding member of Black Sections, also donated to SCS at least once. Sickle Cell Society, ‘Newsletter no.34’ (May 1989), SCS.
OSCAR, as they were known, undertook several successful fundraising and awareness raising initiatives, and ‘gained significant publicity and an increased profile, soon becoming better known than the national group.’ This, Anionwu alleges, ‘caused so many tensions that eventually the local group decided unanimously to break away’, finally forming the Sickle Cell Society. Lola Oni, a health visitor who began working in sickle cell in the 1980s and was closely involved with the Sickle Cell Society at that time, identifies the separation as one in the groups’ respective aims. For OSCAR in the 1970s, she argued, the emphasis was on research, raising money to do research to cure [SCD]. Meanwhile people within OSCAR were saying, you know, look it's all very well to be raising money to cure, but people need support, people need care, people need us to advocate. That's how the Sickle Cell Society came into being.

Both OSCAR and SCS increasingly focused their activities upon supporting patients and families with the social and financial implications of the disease. OSCAR had, by the time of the schism, formed a number of local branches across the country and the schism did not hinder more from being recruited, in Reading, in Nottingham, and in Birmingham to name a few. Clare recalled that OSCAR Birmingham ‘established the precedent of branches operating with a high degree of independence from our headquarters’. In their starkest indication of this they changed their name – retaining ‘OSCAR’ but with the final letter standing for ‘Relief’ rather than ‘Research’, signalling ‘their emphasis on relieving the suffering of patients directly’ and a general disillusionment with ‘the promises of medical research’. Clare himself admitted that ‘over the years the main research that we in London promoted… tended more and

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75 Anionwu, *Mixed Blessings from a Cambridge Union*, 248. This account of the schism is disputed by Neville Clare’s memoir, which recalled that the breaking point came ‘when it appeared that Elizabeth Anionwu had sought backing from the Commission for Racial Equality for her to go on another trip to America, in OSCAR's name, without consulting others on the management committee’, and alleged that Anionwu had signed the committee’s names in support on the application. This culminated in a vote of no confidence, and the members of the Brent branch, ‘wishing to continue her involvement with them’, also left OSCAR. See Clare, *An OSCAR for my troubles*, 123. Anionwu mentions the CRE travel fellowship in Anionwu, *Mixed Blessings from a Cambridge Union*, 253.

76 Lola Oni, interview with GR, 10 April 2018.
more to be into the social aspects of sickle cell provision, and the experiences and needs of the patients in the community and in the hospital setting'.

Crucially, this new approach placed patients and families at the heart of sickle cell activism, and families were a crucial component and site of intervention. The SCS newsletters reveal a tight-knit community, often featuring items announcing the births of members’ babies under headings such as ‘Good News’, advertising family events, and offering condolences to those who had passed away. While this was consistent with a shift in many other condition-specific charities at the time – the Friends of the Asthma Research Council began in 1980 to provide information and support to families in addition to funding research – the focus on the family had a particular resonance in the context of black feminist action. Although white feminist theory perceived the family as a site of oppression for women, black feminists argued that this concept ‘becomes contradictory when applied to the lives and experiences of black women’, as Hazel Carby put it in 1982. Carby and others have shown that the black family under slavery, colonialism and the post-colonial state has been, in the words of Michèle Barrett, a ‘site of political and cultural resistance to racism’. Parents of children with SCD sought to protect and care for their children, and this often involved confrontations with NHS staff. In this sense, the family served to protect individuals and particularly children with SCD, and it was a crucial building block of the sickle cell advocacy movement.

The visibility of the family in SCD activism also offered a counterpoint to what Anionwu described as the ‘direct racism’ they encountered from policymakers, in particular the notion that ‘they [black people] don’t get married’, which was often offered by health authorities as a rationale against implementing carrier and newborn screening programmes. Errol Lawrence argues that the imagined chaos within black families, rooted in a notion of the family as the cornerstone of British society, was an aspect of the common-sense racist ideologies which prevailed in the

77 Clare, An OSCAR for my troubles, 160-1.
80 Elizabeth Anionwu, ‘Community development approaches to sickle cell anaemia’, 10 March 1988, Private collection.
Fig. 3: Sickle Cell Society logo, 1982-90. Sickle Cell Society Archive (uncatalogued).

Fig. 4: Sickle Cell Society logo, 1990 onwards, Sickle Cell Society Archive.
The sickle cell activist movement, centered around mothers and families, offered a firm rebuttal to this stereotype. It demonstrated that the hegemonic 'nuclear family' was present within black communities, but also critiqued this model as 'ethnocentric' (as Anionwu described it) and showed that single parent families were equally receptive to, and deserving of, health intervention. This emphasis on traditional family life was perhaps also partly linked to the Society’s close links with local Christian communities and Black churches. Donors across the years included the Daventry Methodist Church, Willesden’s New Testament Church of God, East Ham’s Congregational & Methodist Church. In 1999 the Society celebrated its twentieth anniversary with a Service of Remembrance and Thanksgiving at Methodist Central Hall in Westminster, with a sermon delivered by Paul Boateng MP. A committee member offered a prayer that began, ‘Lord, we give you thanks and praise for the work of the sickle cell society during the past twenty years, and for the support from many individuals and organisations’.

This emphasis on family, and support from Christian organisations, within the Society was noted by the researcher and activist Sophie Laws, who had worked with SCS in the 1980s. In an oral history interview, when asked if she had told anyone at SCS that she was gay, she responded that she hadn’t as ‘[t]hey would have been horrified… they were very oriented around family life, they simply assumed one got married and had children’. This disconnect described by Laws speaks to wider disconnections along lines of race and sexuality in the women’s liberation movement of the 1980s.

As part of their work on relief and support, SCS was based around support groups and publications aimed at tackling both medical symptoms and social effects of SCD. The Brent support group had first convened in a local West Indian community centre in March 1977. It had been publicised through a radio interview and an advertisement in the newspaper *West Indian World*. In a subsequent publication, Anionwu wrote about the ‘therapeutic effect' that 'meeting anyone else

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82 Anionwu, ‘Health Education and Community Development for Sickle Cell Disorders in Brent,’ 235-7.
84 Sophie Laws interviewed in 1990, Part 10 (Tape 6 F2498), Hall-Carpenter Oral History Archive, British Library Sound and Moving Image Archive.
with the same condition’ had on the sufferers. The group initially provided a space for sharing information and airing grievances, particularly in terms of the lack of information available about the condition, the ignorance of medical staff, and ‘the lack of interest shown by the newspapers, radio and television programmes’, with ‘a feeling of discrimination, of the illness having a low status and that patients were being used as guinea pigs’.85 During the 1980s, various branches of the Sickle Cell Society began to produce reports on SCD, focusing on its clinical manifestation in Britain, the experiences of those who lived with it particularly in terms of their contact with health and social services, and the psychological impact on the sufferers and their families.86 In doing so, they were attempting to address an historic gap in the understanding of SCD. It is clear from the terms ‘sickle cell disease’ or ‘sickle cell anaemia’ that in Western biomedicine, it was defined from the beginning by its pathology – having come to medical attention through technologies such as the microscope, blood electrophoresis, and genetic sequencing, rather than by symptomatic observation. As such, though the mechanism of the disease at the molecular level was well understood, its effects both physical and social were little known. Brozović observed that when she first came to the problem of SCD in 1975, ‘quite a lot’ had been done on the haemoglobin S mutation, because it was ‘fantastically interesting as a genetic issue and a very easy mutation to see, to identify, to follow in detail’. However, she observed that this research did not translate into ‘into either care or the major social issues that transpired… [and] it became more and more clear that it was a social political problem’.87

SCS sought to address this gap in the research. Elizabeth Anionwu interviewed adult patients in 1981 for a symposium on pain held at CMH in 1983, and interviewed both patients and parents for her 1988 PhD thesis, *Health education*

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85 Elizabeth Anionwu, ‘Community development approaches to sickle cell anaemia’, 10 March 1988, Private collection.
87 Milica Brozović, interview with GR, 22 October 2018.
and community development for sickle cell disorders in Brent. On the other side of London, the East London Branch of the Sickle Cell Society 1986 produced the report *Living with sickle cell disease*, supported by a grant from the London Borough of Newham’s Race Relations Unit. The report was authored by Janet Black, a young black graduate, and Sophie Laws, a white feminist activist and researcher. The pair interviewed people living with the illness and their parents. Together, Anionwu, Black and Laws interviewed 38 parents or carers and 32 sufferers. They anonymised their interviewees and responses to questions were often summarized broadly, with short fragments from transcripts included in the text to illustrate a point in the patients’ own words. The results were collective narratives, in which flattened individual narratives into a coherent, unanimous whole, although all texts attempted to draw out the variations as well as the commonalities in the sufferers’ experiences. Black and Laws sometimes turned to tables to illustrate the divergence in opinions among their respondents. The collective narrative was and is a necessary rhetorical device in the realm of patient advocacy during this period. Mold’s work on the patient-consumer movement from the 1970s until 1990 finds that in the early years of organisations such as the Patients Association and the National Consumer Council, patient groups attempted to operate as a collective, before the language of the patient as a consumer was appropriated by Thatcher’s government and incorporated into a language of neoliberal individualism. Texts such as Anionwu’s thesis and the Newham report were written partly to inform design and priorities in services for sickle cell sufferers, and partly as an advocacy tool to draw attention to the present inadequacy of services. Particular flashpoints were diagnosis; education and management of symptoms; and the treatment of sickle cell crises, particularly pain relief.

These surveys constituted an intervention into NHS care. They synthesized patient feedback into broader arcs of experience with the hope that they would inform service provision for people with SCD, and continued to be cited in research

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88 Black and Laws, *Living with sickle cell disease*.
89 Anionwu in *Pain in sickle cell disease* interviewed six sufferers (18); in her thesis *Health education and community development for sickle cell disorders in Brent* she spoke to 22 parents or carers (133); and Black and Laws spoke to the parents of 16 children and 26 adult sufferers (13).
into best practice for treatment for several years.91 This act of speaking the words of sickle cell patients to medical institutions and its staff could be uncomfortable for those on the receiving end. The Newham report in particular was met with some consternation by staff at the local Newham General Hospital, who responded that though ‘[m]any of the grievances expressed by patients were valid… some members of staff felt unfairly represented’.92 At a 1983 symposium about pain in sickle cell disease held at the Central Middlesex Hospital, Anionwu played back the audio of an interview she had conducted with a 17-year-old British-born girl in 1980, who had died two years later. The girl said

I have been going to hospital for, as far as I can say, 11 or 12 years and I haven’t got a permanent doctor yet. They are all just different ones learning what they can, and I don’t like that, not off me anyway… I suppose I’ve got to accept what they give, being in their country.93

As a health visitor playing these words aloud to a room of healthcare professionals, Anionwu contested that Britain was in fact this girl’s country, and that her country had owed her its care. Through these narratives of SCD, SCS and others made a case for a coherent best practice treatment of individuals with the condition.

Critically, these narratives gave voices to individuals with SCD who were often seen by healthcare professionals only in moments of crisis and extreme pain, meaning that they were labelled ‘difficult patients’. Sickle cell support groups, and their access to SCD patients and their families in their lives outside the hospital, were thus able to articulate the confusion and frustration of diagnosis, crisis and hospitalization, and frame those living with SCD not as difficult people, but as people in difficult situations. These interventions sometimes took place in person – Lola Oni recalled

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that representatives from local SCS branches would often be on call to attend the bedsides of patients admitted to hospital.

That was one of the major things that they did, was advocate on behalf of the patients. So they'll go visit a patient, if the patient rings them, say a patient is on the ward and having problems, they'll ring the Sickle Cell Society and say, look I want you to come and act on my behalf and they will come. I mean they won't go there on their own volition, but they will respond to patients who ask for their support.  

The debilitating nature of SCD pain meant that, for some patients, they felt able to call upon the Society and sympathetic nurses to represent them when they were too incapacitated to do so.

Another crucial struggle in the experience of SCD identified by the surveys was the adaptation of the sufferer and their family to the constraints and impacts of the illness. For many, educational literature about the symptoms of SCD was thin on the ground in the 1980s. Several of Anionwu’s interviewees expressed their gratitude for the leaflets and information she provided. One said, ‘Then I met you, with your leaflet, talking to you, it made me realise things that I didn’t think even exist before’. Others recalled that ‘due to the lack of information provided to them that living with… having sickle cell had been a matter of trial and error’, based on observation. A common story was a parent who ‘noticed that after their child came back from a game of football or tennis, and subsequently had a crisis, they would then assume that this was the cause of the crisis, the fact that the child had over-exerted him/herself’, but that others found it took many such crises for them to ‘detect and understand’ the triggers, and so ‘protect' against them. 

This lesson about temperature, exercise and damp is one that many families learned on their own: Black and Laws spoke to one family who determined that swimming triggered their

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94 Lola Oni, interview with GR, 10 April 2018.
95 Anionwu, ‘Health education and community development for sickle cell disorders in Brent’, 172.
96 Black and Laws, Living with sickle cell disease, 58.
daughter’s crises ‘by keeping a diary, thinking through what had happened each day’.\textsuperscript{97} One of Anionwu’s recommendations for healthcare professionals was

That they are familiar with the practical advice that could prevent problems occurring or becoming worse such as the need for a high fluid intake, adequately heated accommodation, ascertaining exercise tolerance and avoidance of over exertion and sudden changes in temperature that can occur with swimming for example.\textsuperscript{98}

Simple instructions such as this percolated through the SCD community, and were rigorously followed by parents who wanted to prevent crises in their children.

In 1983, SCS gathered the information that haematologists, nurses and patients had gathered through a trial-and-error process into a practical manual to advise on the management of SCD. This was later adapted into the 1986 publication \textit{Sickle Cell Disease: A Guide for Families}. This guide combined information about the condition and particularly its inheritance with practical advice about symptoms and disease management as well as guidance on dealing with the social and emotional ramifications of a sickle cell diagnosis. Authored with the Nigerian physician Harun Jibril, the guide was written not just for patients and their families in the UK, but across the world, with an extensive section advising on malaria prevention both for those travelling ‘to a tropical area’ and ‘[i]f you live in a tropical country, for example Nigeria’.\textsuperscript{99} Much of this advice sought to encourage individuals to ask questions of their doctors, as well as translating medical jargon and procedures. Medical jargon was highlighted in bold, followed by a simple explanation of the term. An explanation of blood transfusions was followed by four possible reasons why a blood transfusion might be needed – to alleviate crisis or anaemia, for an operation, or to speed recovery after a stroke – and an encouragement to the patient to ‘[a]lways ask your doctor to explain exactly why you are having a

\textsuperscript{97} Ibid, 44.
\textsuperscript{98} Anionwu, ‘Health Education and Community Development for Sickle Cell Disorders in Brent’, 123.
transfusion’.\textsuperscript{100} Through scripting encounters in this way, SCD activists provided a template for patients to advocate for themselves. This guide coincided with the publication of a spate of patients’ rights guides in the 1970s and 1980s in Britain, such as the 1983 Consumers’ Association and Patients’ Association publication \textit{A Patient’s Guide to the NHS}. Following the revelation in 1963 that NHS patients were used in medical trials without being informed or having given their consent, the Patients’ Association was established and sought to enshrine the right of the patient to consent.\textsuperscript{101} By informing the patient that they could ask the doctor to explain the reasoning behind their medical interventions, Anionwu and Jibril invoked a new, if fragile, patient right to informed consent.

The advice included a step-by-step process for dealing with an individual who is experiencing sickle cell crisis, with suggestions for physical alleviation such as pain relief and hydration, as well as instructions to attend to the person’s emotional wellbeing. ‘A person who is having a sickle cell crisis may become very frightened and tense’, reads one passage. ‘This can make the pain worse. It may help to hold and comfort them to make them relax and feel safe.’\textsuperscript{102} The writers trod the line between writing the book about individuals with SCD, and writing it to them. A section entitled ‘Looking after somebody with sickle cell disease’ was written in the second person, directly addressing the patients. A final point at the end of this section sought to address the emotional ramifications of the condition:

> Although you may be ill from time to time, try not to think of yourself as a permanent invalid. When you are well, try to live as normal a life as possible. Keep an eye on your health but don’t let sickle cell disease take over your whole life.\textsuperscript{103}

This message of hope and optimism is common in the publications of the Society. At the 1993 Sickle Cell Society Symposium, focused on ‘The Psychosocial Aspects of

\textsuperscript{100} Ibid, 61-2.
\textsuperscript{102} Anionwu and Jibril, \textit{Sickle Cell Disease}, 42-3.
\textsuperscript{103} Ibid, 63-4.
Sickle Cell’, 60-year-old Herma Falconer – a longtime supporter of the Society who had been diagnosed 25 years previously – was one of the speakers. The *Sickle Cell News Review* reported that she ‘stressed the importance to the sickler of friends, family and doctors in combating the depression and pain associated with sickle cell’, but concluded that the most important thing was the individual’s attitude. ‘In the end… sicklers have to know how to help themselves and adjust to the disease’, Herma said. ‘I am so happy to have reached 60; I am happy to sit here and say to fellow sufferers – it’s not too bad, you can stand it. I can say to all the younger ones, don’t give up, there is hope ahead’.104 Hope in genetic disease has often been framed along the lines of hope for a cure, for better treatment, or screening, or prenatal diagnosis.105 But in this instance, running alongside the serious concerns that patients had about the services they used and the treatment they received, was a narrative of hope, resilience and control that persevered in spite of sometimes poor treatment. Information and education were crucial to this narrative. Herma emphasised that ‘patients have to know how to help themselves and adjust to the disease’. Another speaker at the symposium, a mother to a child with SCD named Jane Hart, explained that ‘[a]s a parent, your life will be out of control until you can find the key that triggers your child’s crises… Once this key has been found, you can impose some kind of order on chaos and start to give your child a good quality of life’.106 In the effort to render SCD manageable, emotional self-regulation and self-education were framed as the tools that could assist patients and their families.

Sickle cell advocates sought to combat the stigma that existed around SCD and illness more generally in some of the communities they worked in. The contemporary cultural and political discourse on black people and health had made any suggestion of a ‘black disease’ a highly charged subject in both Britain and the United States, particularly following the publication of the works of the psychologists Arthur Jensen and Hans Eysenck, who argued that there were significant differences


in IQ between white and black people. An argument that black immigrants were bringing disease into the country was widely heard during the early 1960s debates over changes to immigration laws, and SCA became a topic of National Front propaganda, portrayed as a terrible disease brought into British hospitals by black nurses. As a result, SCA campaigns were – especially in the late 1970s – met with anger and disbelief. At OSCAR’s first educational talk at the West Indian Student Centre in 1976, the activists heard from the floor several accusations that ‘this whole disease is a concoction of the white man, part of their plan to discredit the black race.’ Clare recalled one conversation between an OSCAR member and a respected community leader, who when asked if he could help with their fundraising efforts responded ‘You people are disgracing us… You are telling people that we black people have disease. A little after this there is going to be big trouble.’ Oni recalled that while working in south London she had known two brothers

Both of them had a child with sickle cell disease, because I did the newborn visit and both of them don’t know they’ve got a child with sickle cell disease. They refuse to tell each other really... When I visited each one I said, ‘oh, have you told your siblings that your daughter’s got sickle cell disease?’ They say, ‘oh, no, no, no. No, no. No.’ ‘No, aren’t you going to tell them? What if she goes to play at their house or stay over the weekend?’ ‘No, she’ll be all right’... they both come to the same clinic, I kept thinking, I wonder if they’re going to bump into each other at the clinic?

The newspaper Black Voice in 1979 ran an article about OSCAR entitled ‘Sickle cell and you’, which exhorted ‘the black community’ to ‘look at sickle cell rationally so they can deal with it’. In 1985, a poem appeared in the Caribbean Times written by Yvonne, an SCS member and parent to a child with SCD. She exhorted, ‘Black people sit back wait for a cure?/Or educate ourselves about this disease/Be

108 Clare, An OSCAR for My Troubles, 90.
109 Ibid, 95.
110 Ibid, 103.
111 Interview with Lola Oni, 10 April 2018.
constructive, stamp it from our race/It's yet another obstacle in our way’.\textsuperscript{113} Clare understood black voluntary organisations like OSCAR to be crucial to raising awareness about SCD, because unlike most NHS doctors, they were a primarily black organisation. The presence of their medical advisor, Dr Eric Stroud of Kings College Hospital, at community meetings sometimes aroused anger, and Clare and other OSCAR members were careful to state that they had approached Stroud and not the other way around. This was to ‘head off accusations that we as an organisation were being used by the white medical establishment.’\textsuperscript{114} In 1989, a former member of the Lambeth Sickle Cell Centre wrote to Edwina Currie suggesting that Eric Stroud and Camberwell Health Authority had misappropriated funds. She lamented that

[t]he sickle cell movement has reached another stalemate because it is still being strangleheld [sic] by incompetent doctors who know how to hog the media, and fool black people into raising funds for useless research, especially research which cannot be seen, or quantified, you know the type which promises a cure for genetic disease. We are very aware how they laugh at us behind our backs and think we are fools[.]\textsuperscript{115}

In 1987, Sally Davies of CMH was met with alarm from the patient community when she brought a proposal for a National Register for SCD and Thalassaemia to several SCS branch meetings. The SCS newsletter reported that

[a]lthough Dr Davies tried to explain her motives for this study, there were a number of undisguised misgivings about the whole concept. The personal opinions of some parents and individuals were coloured by the fear of lack of confidentiality, abuse of data, stigmatisation/labelling and non-consultation with the affected individuals and families.\textsuperscript{116}

\textsuperscript{114} Clare, \textit{An OSCAR for my troubles}, 95.
\textsuperscript{115} Letter, Marion McTair to Edwina Currie, 18 October 1989, TNA JA418/6T/Z/1.
\textsuperscript{116} ‘Sickle Cell Society Newsletter, no.30, November 1987’, SCSHQ.
Davies and others hoped that such a register would help to make an accurate estimate of the number of SCD cases in the country and by area, placing pressure on affected LHAs and RHAs to plan services accordingly. For many patients and their families, the prospect of a central register raised fears of personal or professional discrimination and deeply mistrusted towards NHS bureaucracy and British state, such a suggestion was alarming and threatening.

Efforts to counter the stigma of SCD are exemplified in the debates around the use of the word ‘disease’, and the alternative term ‘disorder’ proposed by some members of the activist community. Clare opted for the latter, explaining that ‘[f]or black people, for historical reasons, the notion of a “disease” carries a special stigma, much more so than is the case in the white British community’. Clare believed this was especially the case for some black men, who ‘would cite the condition and its hereditary nature as “proof” that the children could not be theirs, because there was no way anything resembling an illness or defect could have been inherited from them’.\footnote{Clare, An OSCAR for My Troubles, 98.} Scholars in the social science of health have posited that in many cultural contexts, masculinity and ‘gender role conflict’ inhibit men from reconciling their bodies with illness or frailty, and that for men ‘illness can reduce a man’s status in masculine hierarchies, shift his power relations with women, and raise his self-doubts about masculinity’.\footnote{K. Charmaz, ‘Identity dilemmas of chronically ill men’, in Men’s Health and Illness: Gender, Power and the Body, ed. D. Sabo and D.F. Gordon, (California: Sage Publications, 1995): 268; Will H. Courtenay, ‘Constructions of masculinity and their influence on men’s well-being: a theory of gender and health’, Social Science & Medicine, 50 (2000): 1385–1401.} Karl Atkin et al have argued that black fathers undergoing antenatal sickle cell screening have to negotiate multiple racialized stereotypes around black masculinity and black fatherhood, a process made more fraught by the focus on the female body in pregnancy and feeling targeted on the basis of ethnic origin.\footnote{Karl Atkin, Maria Berghs, and Simon Dyson, “Who’s the Guy in the Room?” Involving Fathers in Antenatal Care Screening for Sickle Cell Disorders, Social Science & Medicine 128 (2015): 212–19.} To avoid stigmatizing those with SCA, OSCAR and SCS chose for a time to describe the condition as ‘sickle cell disorder’ in all their publications.\footnote{Clare, An OSCAR for my troubles, 98.} This became a subject of debate during discussions
concerning the screening programme in the 1990s and 2000s. Lola Oni explained that

some of the patients said they didn't like the term disease, that it's labelling, it's stigmatizing. Other conditions are not called disease, cystic fibrosis is not called disease, it's just called cystic fibrosis. Tay Sachs is not called disease, all these other things are not called disease, why would the one that affects black people be called disease? It makes it seem like black people are dirty and you know, disease-ridden.\(^{121}\)

This change of terminology was successful to an extent and was incorporated for a time into the vocabulary of the state. In 1994, when the Standing Medical Advisory Committee published their report on provision for the haemoglobinopathies, they only used the term 'sickle cell disorder'.\(^{122}\)

SCS sought to rally African and Caribbean communities around the cause, and responded forcefully when they felt that the cause of SCD had been politicised to the extent that some were making money from it. In 1988, one SCS newsletter expressed anger about a fundraising dance that had taken place that July. Held at the Tudor Rose in Southall, it saw ‘one of the largest gatherings of young black ravers… They had come in response to the appeal to support the Society and of course had to be entertained by an impressive line-up of local black talent’. However, the newsletter complained, ‘after the “line up” and the owner of the Tudor Rose had been paid their substantial fees’ only £125 was left to SCS. This state of affairs was condemned in the SCS newsletter as ‘deplorable that members of our own community, instead of using their God-given talents to bring benefit to sickle cell sufferers, seek only to exploit and gain financially through their misfortunes’.\(^{123}\)

SCS drew upon the community they had created not just for financial donations but also for the donation of that valuable medical resource – blood. Even the earliest SCS newsletters appealed to readers and supporters for blood donation,

\(^{121}\) Lola Oni, interview with GR, 10 April 2018.
\(^{123}\) Sickle Cell Society, ‘Newsletter no.33’, (November 1988), SCSSHQ.
the social responsibility of the sickle cell community to donate not just money, but to draw upon their common ancestry to save the lives of other members within the group. This issue was critical for the treatment of SCD, because the ‘minor blood group differences between Whites, Mediterraneans, Blacks and Asians’ – usually of little importance during transfusions – could put people with blood group variations found among those of African origin at risk of alloimmunization.\textsuperscript{124} A November 1982 newsletter ran a piece which entreated the reader:

\begin{quote}
YOU might have that special blood group that is desperately needed for patients with sickle cell disease who may need urgent blood transfusions at any time. PLEASE DON'T LEAVE IT TO OTHERS – GIVE BLOOD NOT EXCUSES AND HELP US TO HELP OTHERS.\textsuperscript{125}
\end{quote}

The use of the term ‘excuses’ here speaks to a sense of collective responsibility. In April 1983, medical workers from the North London Blood Transfusion Centre ran the London Marathon for the Society, wearing Society t-shirts.\textsuperscript{126} In June 1984, the BBC radio programme \textit{Black on Black} launched a four week campaign to raise awareness about the importance of black people giving blood.\textsuperscript{127} SCS received over 800 calls and letters from the public, with many expressing that they had been turned away from their local blood donation centres.\textsuperscript{128} SCS followed up a year later with a poster campaign on London public transport, designed by Laurel Brumant – a young woman with SCD whose artwork was often used for their causes – and were featured on the Channel 4 programme ‘Help!’ in May 1985.\textsuperscript{129} As a 1985 newsletter item put it, with dark humour, ‘[w]e don't need every drop of your blood but we need some’.\textsuperscript{130} By 1994, the Society had linked up with the South Thames Blood Transfusion Service with a campaign called ‘The Perfect Match’. The accompanying

\textsuperscript{125} Sickle Cell Society, ‘Newsletter no.9’, November 1982, SCSHQ.
\textsuperscript{126} Sickle Cell Society, ‘Newsletter no.11’, April 1983, SCSHQ.
\textsuperscript{127} Sickle Cell Society, ‘Newsletter no.19’, September 1984, SCSHQ.
\textsuperscript{128} Sickle Cell Society, ‘Newsletter no.21’, February 1985, SCSHQ.
\textsuperscript{130} Sickle Cell Society, ‘Newsletter no.21’, February 1985, SCSHQ.
leaflet explained that though 800 patients with sickle cell disease were registered in the South Thames region, there were less than 300 ‘African or Afro-Caribbean’ blood donors.\textsuperscript{131} These blood donor campaigns illustrate Tapper’s observation that ‘sickling affects not only individual sick bodies – those suffering from sickle cell anemia – … but [also] an entire community or social body’.\textsuperscript{132} In this instance, sickling not only affected the African and Caribbean communities in London, but also invoked a sense of embodied responsibility predicated upon a sense of shared ancestry even in those who did not have sickle cell trait. Finally, this example is also indicative of the relationship between SCS and conceptions of biological and cultural ideas of ‘race’. Troy Duster has used the case of alloimmunization in SCA to illustrate that the elimination of the discussion of race and ethnicity from medicine can obscure the needs of those outside the dominant framing of public health and medical research. In this case, the overrepresentation of white European people in the blood donor pool of South Thames could have a negative effect on some sufferers of SCD. Part of SCS policy was therefore to lean into ‘the interaction of race… however flawed as a biologically discrete and coherently taxonomic system – with feedback loops into the biological functioning of the human body, and then again in relation to medical practice’.\textsuperscript{133}

\textbf{The Sickle Cell Society, Brent Sickle Cell Centre and the Welfare State, 1979-1994}

This final section will discuss the blurred lines between the Sickle Cell Society, the Brent Sickle Cell Centre and the British welfare state. SCS was funded by central and local government, as well as by fundraising from black communities. The SCS office was based for a time in Central Middlesex Hospital, while the Brent Sickle Cell Centre was sited in the smaller Willesden Hospital, centred in the community. These two organisations, the Brent Sickle Cell Centre and SCS, occupied a liminal space

\textsuperscript{131} South Thames Blood Transfusion Service / Sickle Cell Society, ‘Are you the perfect match?’ leaflet, c.1994, Private collection.  
\textsuperscript{132} Tapper, \textit{In the Blood}, 98.  
\textsuperscript{133} Duster, \textit{Buried Alive}, 272-3.
between community and National Health Service. Non-governmental organisations (NGOs) have been integral to the NHS since its inception, not least because the existing healthcare infrastructure the welfare state absorbed in 1948 was primarily made up of NGO hospitals – for example the Marie Curie Hospital in Hampstead. The Brent Sickle Cell Centre also followed in the footsteps of black activists in Britain who, seeing that institutional racism in the educational system meant that the state was failing their children, continued the Caribbean tradition of supplementary schools in Britain. By 1981 (when the Brent Sickle Cell Centre was founded) there were 41 supplementary schools in London alone, with more in Bradford, Leeds, Nottingham and Wolverhampton. The Centre was a model that became influential across Europe, cited as best practice for community screening for minority communities.

The close relationship between SCS and Central Middlesex Hospital was such that SCS newsletters sometimes thanked ‘the staff of Ward B4 and E1’ after the hospitalizations and recoveries of SCS members. In 1984, the Society’s newsletter ran an item about the possible closure of Central Middlesex Hospital, which had over 180 SCD patients attending. As a result of the ‘high standard of education and in-service training they had received over the last seven years’, the SCD centre at the hospital was rare in the service landscape for its compassionate care of patients. Lola Oni, who later began working at the Brent Centre after several years working in Lambeth, explained that she had always thought of SCS and the unit at CMH as

almost like twins. Because they were born the same year, and because they almost like evolved out of each other, because it was the effort of the voluntary organization as well that then help to get the sickle cell centre established. Because they were saying, look we need support, and so were

135 Waters, Thinking Black, 131-4.
137 Sickle Cell Society, ‘Newsletter no.19’, September 1984, SCSHQ.
138 Sickle Cell Society, ‘Newsletter no.16’, January 1984, SCSHQ.
Dr Misha Brozović, and the members of the Society, that's how things came about.\textsuperscript{139}

The Brent Sickle Cell Centre was part of the haematology department at CMH, and for several years the Society rented a room from the Health Authority in a room adjacent to the Centre. Anionwu observed that ‘[t]he fact that the Centre, based within the NHS, could be confused with a national black community was, I feel, evidence of the breaking down of traditional bureaucratic barriers that exist in the health service’.\textsuperscript{140}

While many such as Jocelyn Wolfe and Stella Dadzie perceived the role of SCS as ‘awareness raising’ among the affected communities and the health services, the charity also supplemented roles usually performed by the state. As early as 1981, the Society raised £1,800 for laboratory equipment for Central Middlesex Hospital, and it was recorded in the newsletter that ‘[i]t is now installed at the hospital – thanks to everybody who helped us achieve our target’.\textsuperscript{141} The funds were raised in a variety of ways, including through a gospel concert organized by the Chiswick Seventh Day Adventist Church, which raised almost £900. In 1982, the Society launched an appeal for £5,000 for a ‘computer/word processor’ for the Sickle Cell Centre in Willesden General Hospital, and in a fundraising update recorded that £600 was raised towards this by a raffle at an event organized by the Joint Dominican Development Associations.\textsuperscript{142} Black community groups such as these funded the administrative and pathology costs of the NHS Sickle Cell Centre, where patients were treated.

This type of charitable investment in the NHS was not unique in this period. The hospice movement of the 1960s and 1970s – including the Marie Curie Foundation and the National Society for Cancer Relief (now Macmillan Cancer Support) – built hospices around the country which the NHS would operate and fund, and during the 1980s Macmillan paid for the first three years of over 500 hospice

\textsuperscript{139} Interview with Lola Oni, 10 April 2018.
\textsuperscript{140} Elizabeth Anionwu, ‘Community development approaches to sickle cell anaemia’, 10 March 1988, Private collection.
\textsuperscript{141} Sickle Cell Society, ‘Newsletter no.3’, April 1983, SCSHQ.
\textsuperscript{142} Sickle Cell Society, ‘Newsletter no.7’, June 1982, SCSHQ.
nurses’ contracts before they were taken over by the NHS. Reflecting on their organisation’s role during a Wellcome Witness Seminar, Rosie Barnes of the Cystic Fibrosis Trust (CFT) remarked that part of the role of the charity was to ‘try to fill the gaps in what the state just won’t or can’t do, so apart from the database which we fund, we have funded quite a lot of complex work and facilities in the area of microbiology that just might not have happened had the Cystic Fibrosis Trust not facilitated it.’ This shift was observed in the mid-1980s, which may reflect both the increasing purchase of the ‘patient-consumer’ in this period and progressive underinvestment by the Conservative government in the NHS. However, where the work of OSCAR and SCS had pivoted entirely to patient and family support and to supplementing the work of the Brent centre, the CFT did not abandon its investment in scientific work on cystic fibrosis. One former Chairman of the CFT remarked that ‘the amount of money we put into laboratory research and scientific research, as opposed to clinical research and the support of the NHS, didn’t seriously fall, because the amount of money being collected gradually rose’. The Trust had been set up by two wealthy businessmen, John Panchaud (who had a daughter with CF) and Joseph Levy, in 1964, who both contributed significant sums of their own money to the cause. Reflecting on the origin of these donations in 2008, the secretary, Rosie Barnes, reflected that much of the money came from families affected by cystic fibrosis and their schools and workplaces. ‘Very often the big donations we get from companies will come about as a result of somebody on the inside, perhaps with a child with [CF], asking their company to bear us in mind when making their charitable donations for the year’.

143 Rossi, Fighting Cancer with More than Medicine, 177.
144 Rosie Barnes quoted in E M Tansey and D A Christie, Cystic Fibrosis: The Transcript of a Witness Seminar Held by the Wellcome Trust Centre for the History of Medicine, (Vol. 20, 2004): 37.
145 Anthony Jackson quoted in Tansey and Christie, Cystic Fibrosis, 40.
147 Barnes quoted in Tansey and Christie, Cystic Fibrosis, 37.
communities generally more impoverished than the white communities affected by CF – are shown starkly in the comparative fortunes of the two charities.

By contrast, for SCS many of their patients and their families had little expendable income to provide to the charity – quite the opposite. Not only did SCS supplement the NHS in its provisions, but it also supplemented social services in order to provide patients with the condition. In 1983, in response to approaches from social workers, health visitors and community workers, the Society began administering a separate welfare fund for families affected by SCD who were experiencing financial hardship. These grants often focused on literally keeping individuals warm by paying for clothes or heating bills, due to the connection between cold temperatures and sickle cell crises. One grant of £150 was awarded on the recommendation of a counsellor to a 14-year-old girl whose frequent hospitalisations were ‘believed to be due to lack of appropriate clothing’, and whose mother’s illness limited the family income.148 SCS drew on the knowledge and access of welfare state personnel to decide who was in need – applications for welfare had to be supported by evidence from counsellors, social workers or general practitioners to be successful.149 By 1986, the annual Jeff Johnson Memorial Bike Ride – a fundraising fixture in the SCS calendar – was devoted to raising money for the fund.150 A 1993 newsletter emphasized that the numbers of applications for welfare support had dramatically increased, as well as stating that a number of applications had come from individuals without SCD, although the constitution restricted the funds only for people with sickle cell disorders.151 By 1994, the Society was awarding a total of £12,000 welfare grants per year.

Why was this welfare fund needed? In 1983 the SCS committee reported that they had ‘endeavour[ed] to try and obtain as much help from the statutory services as possible but have been informed that there are no funds or have encountered delays in cases where urgent help is needed’.152 Those suffering with SCD were often unsuccessful in their claims for benefits such as Disability Living Allowance.

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150 Sickle Cell Society, ‘Newsletter no.27’, December 1986, SCSHQ.
(DLA) because of the variability of the condition – in which some individuals will be ‘only mildly affected’ and require little support, while others are very badly affected and need assistance with personal care and mobility.\textsuperscript{153} Moreover, the severity of the condition varies even in the same individual, who for many weeks or months may be healthy and able to work, before a sudden crisis might require rest or hospitalization for several weeks or months, seriously disrupting the individual’s ability to hold down a job unless under a very understanding and accommodating boss. The disadvantages of living with SCD were multiplied by the overlap between race and class, in which black people were continually discriminated against in employment and housing. Between 1973 and 1976 the unemployment rate had gone up twice as fast for black people than it had for white people in Britain. The PEP reports found that in south-eastern England, black households were five times more likely than white households to have shared dwellings, a circumstance which Peter Fryer observed had ‘long-term effects… on children’s health and welfare… and the problems thereby caused for women – especially mothers of babies and young children – scarcely need emphasis’.\textsuperscript{154} SCS sought to counter these effects with its welfare fund, and the need for this fund is also indicative of why the Society rarely received the large donations received by organisations such as the CFT.

The symbiosis between voluntary organisations such as SCS and the NHS itself was crucial to the improvements in SCD treatment in Britain. Lola Oni explained that

I work for the NHS, they pay my salary. I can only criticise to a certain degree. Yeah, but if you’re aware that there are things that are a threat to good services or to good patient care, you know, you’ll ensure that the patients are aware of that, or that the voluntary sector is aware of that. So maybe they’re the ones that would need to raise that with the policymakers because it certainly can’t be me.\textsuperscript{155}

\textsuperscript{153} Sickle Cell Society, ‘Finding your way around the benefits system’, c.1993.
\textsuperscript{154} Fryer, Staying Power, 389.
\textsuperscript{155} Interview with Lola Oni, 10 April 2018.
Critical to the success of the sickle cell cause, Oni explains, has been the establishment of voluntary organisations that allowed individuals – who are often still healthcare professionals – to criticize specific NHS and DHSS policies from a different position. It was crucial, however, that these organisations be closely linked to those in healthcare roles. ‘The voluntary organizations are not part of the NHS, they don't know what's going on in it’, Oni explained. ‘It's only the people in the NHS that know what's going on the NHS.’ At the same time, it was often the patients who perceived the ‘smoke signals’ first because ‘they're the ones that are experiencing either bad care on the ward or you know, poor management in A&E, or whatever it is.’ In Oni’s analysis, spaces such as the specialist centres – which were part of the NHS but often had close ties to local voluntary organisations – were essential intermediaries between top-down policymaking and bottom-up patient feedback. She emphasized, however, that this dynamic was not unique to SCD but found also in the communities of patients, advocates and healthcare professionals that formed around genetic conditions such as cystic fibrosis and haemophilia. The crucial difference, Oni argued, was in the access of these communities to ‘influence’. As conditions that affected the majority white population of Britain, when powerful politicians, policymakers and journalists tended to be white themselves, haemophilia and cystic fibrosis had voices in spaces of influence. This question of access and influence was a critical concern of SCD groups. In her 1990 interview, the white researcher Sophie Laws recalled that her work with the Newham SCS branch made her ‘conscious of how very aware of race they were’. She illustrated this perceived awareness with a telling example:

although as I say they weren’t sort of like militants, if a new worker was appointed, say in like social services or somewhere, the first thing they wanted to know is were they black or white… it was very very clear that that was the case, and they would sometimes do that and say oh sorry Sophie, we don’t mean anything bad[.]\(^\text{157}\)

\(^{155}\) Ibid.

\(^{157}\) Sophie Laws interviewed in 1990, Part 10 (Tape 6 F2498 Side A), British Library Sound and Moving Image Archive.
Although Laws did not offer any thoughts on why racial identity was so important to the group even though they were not ‘militant’, it is likely that the group’s experiences had led them to expect positive action for black communities to come mostly from black figures of authority. They were not alone in this analysis. Jerry Lewis, who worked in local government in north-eastern inner London in the same period, observed that competition for local voluntary sector funds was fierce, and ‘many black and ethnic minority councillors saw themselves—as indeed many white councillors from wards dominated by council estates saw themselves—as arguing for their power base, which was often centred on voluntary sector organisations from within their own communities’. ¹⁵⁸ Local funding was critical for SCS and OSCAR, and it was often more generous than central funding. In 1982, both SCS and OSCAR relied on the Greater London Council for grants from their Ethnic Minorities Unit. In 1985 SCS received £15,000 from the GLC, compared to £13,000 received from DHSS (see Chapter 2). ¹⁵⁹

Lola Oni observed that it was only when the cause of SCD was picked up by celebrities such as the broadcaster Trevor MacDonald, the comedian Lenny Henry and Wilfred Wood, the first black bishop in the Church of England, that the issue began to gain traction. ¹⁶⁰ By the 1990s, individuals such as Elizabeth Anionwu (appointed a Dame in the 2017 New Year Honours) and Sally Davies (appointed a Dame in the 2009 New Year Honours and appointed Chief Medical Officer in 2010) were crucial to decision-making groups such as the Standing Medical Advisory Committee which reported in 1994. Celebrity involvement appears to have been crucial, both in politicizing the issue for a wider audience and attracting the notice of health ministers. This sense of alienation was explicitly picked up by Junior Health Minister Baroness Cumberlege, in an article for the SCS newsletter in 1993. The footballer Garth Crooks had said in a previous SCS newsletter that ‘Sickle Cell is a British problem affecting British people’. This, Cumberlege said, ‘caught my attention… The recognition that sickle cell disorder is a British problem – not

¹⁵⁹ Sickle Cell Society ‘Newsletter, no.24’, December 1985, SCSHQ.
¹⁶⁰ Lola Oni, interview with GR, 10 April 2018.
something marginal – reflects wider principles of equity which lie at the heart of what the Government is trying to achieve generally for the health of people from black and ethnic minority groups’.  

Conclusion

The roots of sickle cell advocacy lay in the British Black Power and the Black British women’s movements of the late 1960s and 1970s, members of which saw the condition as an opportunity to identify the operation of institutional racism within the NHS, with ramifications for broader issues of ethnic minority health. Founders, such as Neville Clare, rhetorically linked the illness with the contemporary architecture of British state racism and to legacies of colonialism and slavery, but also found in the condition a link to diasporic African identities that brought them closer to lost genealogies. While OSCAR had originally been founded with a mission statement of scientific research and curative medicine, this quickly shifted towards the provision of support for families, the articulation of patient rights within the NHS system, and government lobbying for basic care for the condition. With the small grants provided to them by Inner City Partnerships and the GLC as well as community fundraising, these groups sought to provide what the state did not – equipment for the local specialist sickle cell centre, welfare grants for families, and information. As organisations primarily run by black people, they were well placed to undertake some of their most sensitive work – raising awareness about the condition among African and Caribbean communities (among others) who were understandably wary, given their experiences of medical racism and resultant mistrust of a predominantly white medical community.

The organizations that sought to promote fundraising and policy around SCS became ideal candidates for the differentiated incorporation of Black and Asian interests into the state that some have tied to the decline of black radicalism in the late 1980s. Many of its activists were healthcare workers based within the NHS, or

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161 Sickle Cell Society, ‘Sickle Cell News Review’ (May 1993), SCSHQ.
patients themselves, who saw the battle for improvements in sickle cell treatment as one fundamentally tied to medical institutions and to recognition from the state. In some senses, this was true – the supporters of SCS and OSCAR included organizations such as churches, and individuals who were more comfortable with single-issue activism that was progressive but less overtly political. SCS and OSCAR also adopted the approaches of other condition-specific medical charities for their own ends. But at the heart of this activism was a keen awareness of the locations of power in the British state bureaucracy at the levels of local and central government, and a dense documentation of, and resistance to, state indifference and racism. The healthcare workers involved in SCS found that the ‘outsider’ status of their voluntary organization enabled them to criticize and lobby the state for action, in ways that their positions as state workers did not. Moreover, black women were at the heart of this movement and positioned black families at the heart of activism, rejecting the cultural racism that had stymied the development of sickle cell policy and interventions for so long.
Chapter 5: Embodied citizenship: Patient experiences and narratives of sickle cell disease

In 1985, the Sickle Cell Society collected the proceedings of a symposium they had organised at Central Middlesex Hospital on the subject of pain in sickle cell disease into a single volume. The volume – as the symposium had also done – incorporated presentations from medical experts with the experiences of SCD patients in hospital during their crises.1 One chapter was a collection of personal accounts, told at length, of sickle cell crises by anonymous contributors. These narratives focused on the experience of exclusion and neglect that many with SCD experienced in British hospitals as they sought treatment under difficult circumstances. The book was also illustrated with a number of drawings by children with SCD. Two such images, one by Georgina Edema and the other by Laurel Brumant, are impressionistic compilations of SCD experience. These dreamlike collages have a few commonalities: medical paraphernalia such as bedside tables covered with pill bottles and blood bags, and visual metaphors for pain such as screwdrivers and axes chopping wood. Brumant also drew two indifferent white nurses. In the centre, portraits of herself, her mother and father are framed like a genetic inheritance diagram, with the distinct features of her parents partially obscured by crude black and white masks. Beneath the parents, the face of a child – presumably Brumant herself – has a sickled cell on her forehead, possibly a reference to the American scientist Linus Pauling’s infamous 1968 recommendation that individuals with the sickle cell trait should have the information tattooed on their forehead, to prevent them from having children with another carrier.2 In this drawing, Brumant recorded the nurses who treated her, looked at herself and her parents, and observed how others might see them as a family affected by SCD. In Edema’s picture, a child is silhouetted against a black and white checked tiles, looking onto a scene of

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1 Sickle Cell Society, *Pain in sickle cell disease – ‘I know you are in pain, but would you mind answering a few questions?’ Proceedings of a symposium held at Central Middlesex Hospital on 7 December 1983* (National Extension College and Sickle Cell Society, 1986).

Fig. 6: Drawing by Georgina Edema, in Sickle Cell Society, *Pain in Sickle Cell Disease* (National Extension College and Sickle Cell Society, 1986): 16.
traditional West African huts, palm trees, and a boat. In the centre, a figure – perhaps Edema herself – sits, with a globe at her right shoulder, showing Africa and Europe. Her picture both encapsulates her physical experience of her illness and suggests a connection being made with the homeland of her parents or grandparents. In these pictures, Edema and Brumant depicted the symptoms of their disease – visualising their pain, sickled cells and the medications they needed – but also reflected on the broader circumstances of their lives and the other meanings, familial and geographical, that their illness held for them. The young artists placed the sickled cells, which had long been an object of fascination from scientists and of confusion from policymakers, within the context of family, home, hospital and heritage.

Thus far, this dissertation has viewed ‘sickle cell anaemia’ from the perspective of biochemical researchers and anthropologists, health policymakers and doctors, and sickle cell activists. From these perspectives, particularly those of the 1950s and 1960s, the ‘sickle cell patient’ was glimpsed as an abstract, anonymous frequency – represented by cross-hatching across sub-Saharan Africa on maps of the world, or large black spots on English cities. Patients were identified in casebooks, like the nine-year-old whose blood sample was sent to the Cambridge Abnormal Haemoglobin Unit by one R.W. Richardson at Coventry and Warwickshire Hospital in 1963. In DHSS files, the stories of individuals such as Stephen Bogle or Joyce Bogle occasionally made their way to policymakers’ desks, usually because of their untimely deaths. By the early 1980s, less fleeting glimpses of the experiences of people with sickle cell anaemia were found in the outputs of sickle cell activists and healthcare professionals such as Elizabeth Anionwu and Milica Brozović. These included detailed, interview-based surveys of sickle cell patients and their families and carers, in order to identify gaps and inadequacies in the National Health Service’s awareness and provision for the condition. The experiences of people with sickle cell disease, in their own words, surfaced more and more in this period. SCS publications often employed these narrated experiences with policy and attitudinal

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4 Sample received 7 October 1963, MRCAHU Casebooks, Papers of Hermann Lehmann, Whipple Museum for the History and Philosophy of Science, Cambridge University Libraries.
changes in mind. The experiences of individuals living with the condition were included in symposiums about the condition throughout the 1980s and 1990s, with patient voices sometimes literally played to rooms of doctors. By 1994, DH itself was incorporating the words of people with SCD into a series of pamphlets aimed at helping commissioners provide local services. These reported experiences often dealt with the issue of difficult and charged encounters between patients experiencing the painful sickle cell crisis and their doctors over pain relief (see Chapter 3). As discussed in the previous chapter, these voices were often subsumed into collective narratives, with common themes such as pain relief, distressing diagnosis, and poor treatment.

Georgina Edema and Laurel Brumant’s drawings invite a different perspective onto the experiences of people with SCD. While these drawings were published in the health policy publication about pain, they also provide glimpses of the meaning these young artists made of their condition beyond that pain. Their observations of the nurses who treated them and the spaces and medicines they were treated with positions them as subjects, rather than objects, in this medical setting. In many of the primary sources that inform the preceding chapters, SCD patients and their families were under scrutiny. But in this case, Brumant and Edema were doing the looking, because of course SCD patients were also viewers as well as objects of scrutiny. As Perry has argued, in migrating to Britain during the post-war period, people from the Commonwealth invoked their citizenship and contested what it meant to be British.\(^5\)

The previous chapter showed, in entering the spaces of the NHS and researching, lobbying and delivering treatment for the SCD, activists, parents and patients performed that citizenship over and over. This chapter will explore how, in doing so, patients and their families made sense of their experiences with SCD and the welfare state. In the words of Byron J. Good, ‘[r]ather than the body as a site of domination or an object of medical practice’, I will focus on the body ‘as a creative source of experience’ of citizenship and lives lived in close contact with the NHS.\(^6\)

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The lives, experiences and identities of people living with SCD in the period 1948-1996 (and beyond) were touched by three radical post-war shifts. Firstly, as members of the ‘Windrush generation’ and their descendants, these patients were the first large population of black people to build their lives in postcolonial Britain, enduring deep hostility from the white population and both violence and indifference from the state.\(^7\) Living with lifelong illnesses, they also witnessed a reformulation of how patients were seen and treated within the NHS, tracking a shift from paternalism to patient-centred care – and also emergent ideas of health citizenship.\(^8\) The post-war period also saw an explosion in genetic knowledge, and families living with SCD in this period were some of the first to live through what Kaja Finkler has called the ‘medicalization of family and kinship’.\(^9\) This chapter also sits in several broader traditions of scholarship, particularly a range of practices grouped loosely round the anthropology of biomedicine, such as the ‘patient’s view’ discussed by Roy Porter, the work of Michel Foucault, and Arthur Kleinman’s conception of ‘illness narratives’.\(^10\) I will use published sources of SCD patients’ experiences, the art and archives of Black British artist Donald Rodney, and oral history interviews I conducted in the UK between March and December 2018 to explore how new formulations of citizenship, safety and belonging (or their opposites) were experienced.

Accessing ‘experience’ is a problematic goal for the historian. Joan Scott critically dealt with the ‘evidence of experience’, and argued that it can reify difference when historians do not problematize it. Without historicizing experience or


\(^8\) As discussed in more detail in Chapters 2 and 3. Mold et al comprehensively discuss the different forms of health citizenship in the post-war period in *Placing the Public in Public Health in Post-War Britain, 1948-2012* (Palgrave Macmillan, 2019): 134-6.


historicizing the identities it produces, the resulting work fails to explain how
difference and identity are relationally constituted products of their time. Scott says
that ‘[e]xperience is at once always already an interpretation and something that
needs to be interpreted. What counts as experience is neither self-evident nor
straightforward; it is always contested, and always therefore political’. Problematising, historicising and interpreting experience leaves space to
acknowledge the subjectivity of the historian herself, ‘for deciding which categories to
historicize is inevitably political, necessarily tied to the historian’s recognition of his or
her stake in the production of knowledge’.11 This is especially true for the practice of
oral history, in which the interviewees’ answers are parsed through the interviewer’s
idiosyncratic perspective, priorities, and frame of reference.12 Undoubtedly my
choices of interviewees, questions and subsequent analytical paths have been
shaped by my subjectivity as a white woman, and this positionality has shaped how
my interviewees have responded to me (I have discussed this further in the
introduction to this dissertation). I recruited my interviewees by promoting an
advertisement for participants through the Sickle Cell Society. I interviewed 13
people living with SCD or family members who expressed interest when they saw
the advert, and was put in touch with several more.

This is, of course, a self-selecting group. The most obvious factor in
interviewees’ willingness (or not) to be interviewed was gender. Of the 13
interviewees, 11 were women. Of the two men I spoke to, one asked for his wife to
be present, and the interview ultimately became a joint interview. The absence of
male voices in this chapter may be one way in which my positionality as a white
woman has shaped the interviews. It may be also due to the ‘major disruption’ to
masculinity posed by chronic illness, and there have been many studies illustrating
that men as a group are less likely to disclose health issues or seek help regarding
them. Given that the call for participants was titled ‘Tell Your Story’, perhaps men are
less likely to have a formulated illness narrative that they feel comfortable discussing

Downs, ‘If “Woman” is Just an Empty Category, Then Why Am I Afraid to Walk Alone at Night?
Identity Politics Meets the Postmodern Subject’, Comparative Studies in History and Society, 35:2
(1993): 414-37; and Joan Scott, ‘The Tip of the Volcano’, Comparative Studies in History and Society,
with a stranger, or they have illness narratives predicated on traditional masculine practices such as staying ‘strong and silent’ which are incompatible with agreeing to discuss their health. Masculinity may well intersect with ‘race’ and disability to produce different experiences and narratives around illness. The effects of these intersections are not simply that of doubling or trebling the weight of discrimination but, as Kimberlé Williams Crenshaw writes, take on specific new forms of meaning. She explains that

Black men and women live in a society that creates sex-based norms and expectations which racism operates simultaneously to deny; Black men are not viewed as powerful, nor are Black women seen as passive. An effort to develop an ideological explanation of gender domination in the Black community should proceed from an understanding of how crosscutting forces establish gender norms and how the conditions of Black subordination wholly frustrate access to these norms.

The reluctance of men to be interviewed for this project, and their lesser representation in sickle cell activism (see Chapter 4), as well as the reported experiences of women being held responsible for SCA in their children by their partners, must be viewed through the intersections of gender, race and disability. Given the skew of oral sources this chapter cannot interrogate the lives of men who live with the condition, or male family members. Despite this, this chapter will follow Crenshaw in considering how the intersections of ‘race’, gender and disability have shaped the experiences of women living with SCD. As Bryan, Dadzie and Scafe argued, ‘because we are women, the Health Service is central to our lives. We cannot avoid using it. It is us who bear the brunt of the responsibility for our own and

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our families’ health’. As women, their bodies were medicalised (and centred as carriers of SCA) through their experiences of giving birth, and they were more likely to be their child’s primary caregiver; as black people, they were subjected to racist stereotyping by medical staff; and as people with a long-term chronic condition, they experienced discrimination in employment which was legal until the mid-1990s.

The historicizing of experience commanded by Joan Scott is complicated by the years, often decades, between the events being recalled and the interview. Although this dissertation deals with events between 1948 and 1997, through oral histories we are also dealing with dynamic identities and memories in flux and formation until 2018. Some – though by no means all – of my interviewees were or had been part of SCA support groups. Many of the stories recounted to me may have been recounted before, in a process of shaping and building a sickle cell community. Rebecca Jennings has discussed how the concept of ‘composure’, both in terms of how a narrative is ‘composed’ and the narrator finding a ‘sense of composure’ in telling their story, ‘is at the heart of personal narratives’. Stories may have been formulated and reformulated in retellings over the years, and the appropriate ‘composure’ and compositions are also contingent to the moment of telling. These layered and contradictory identities, beliefs and memories can be seen in choices of vocabulary. In much of the 1980s literature on sickle cell from the activist community, the term ‘sickler’ was a commonplace word to describe individuals with SCD. Some interviewees who lived through the 1980s used the term when recounting their memories in oral history interviews, but when asked about it, expressed discomfort with the term. Though Helen used the word reflexively while telling a story, she later remarked that ‘I’d prefer somebody not to say ‘she’s a sickler’, I’d prefer somebody to say ‘she suffers from sickle cell disease’.’ Suzanne, a doctor and a person with SCD, explained that

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17 Helen (pseudonym), interview with GR, 14 August 2018.
saying ‘sicklers’ is like saying ‘a diabetic’, and you’re not supposed to do that, doctors are not allowed to – well we’re supposed to say a patient with diabetes… You’re supposed to see the person. But that’s just because of my training. I mean, yeah you’re not the gallbladder in bed 9, you’re Mrs Smith, with gallstones.18

This rhetoric may be reflective of a shift within the last thirty years towards patient-centred care in the NHS, with health policy research addressing the need to ‘[see] the person in the patient’, and the rising profile of patient advocacy groups.19 That some people slipped in and out of using the term as they told their memories but disavowed the word when asked, and that the term ‘sicklers’ frequently surfaced in the patient literature of the 1980s, is indicative of layered memories, identities and opinions being reviewed and reconciled across a person’s lifetime. As Jennings reflects, selfhood and identity are ‘a cultural construction which is specific to a given historical period’ and oral histories cannot accurately capture the ‘true’ selfhoods and identities of the past – they are inevitably inflected with the cultural imperatives of the present.20

This thesis has argued that in entering medical spaces and claiming the right to heal and be healed, sickle cell patients and black healthcare workers claimed a substantive citizenship. Chapters 3 and 4 argued that the healthcare professionals and voluntary workers who created and funded clinics, equipment and support groups for the treatment and support of SCA made a claim for the entitlement of Black British people to the care of the state, outside the realm of radical political action. This chapter argues that claims to citizenship were also made outside this organised activism, in everyday encounters between the individual, the family, and the health service. As the drawings of Georgina Edema and Laurel Brumant show, these encounters were experienced, enacted and known through the body. This chapter uses the concept of ‘embodied citizenship’ to access experiences of pain

18 Suzanne (pseudonym), interview with GR, 16 April 2018.
and relief, care and control as emotional experiences of alienation and belonging.\textsuperscript{21} How the patient and their carer experienced, managed and represented the symptoms of SCD can be seen as performances of their own individual and contingent relationships with the state and the family. Claims for care and belonging were mediated through physical and emotional experience, and must be seen as part of what Perry calls ‘a historical continuum of citizenship practices and imaginaries of belonging that shaped the evolution of race politics and the formation of postcolonial Black Britain’.\textsuperscript{22}

This chapter will begin with an examination of the life and work of the artist Donald Rodney, arguably one of the most prominent British figures to live with SCD. In his short but prolific career between 1982 and 1998, Rodney increasingly staged his own body, and his illness, to make interventions in the construction of British national identity, black masculinity and state power. An examination of how Rodney used his condition as a reference point and canvas for his artistic outputs tells us much about the condition as a symbol of blackness or politically charged ‘moving signifier’. Rodney’s life, artistic methods and the structure of his archives, illustrate that for him the hospital could be a site of creativity and meaning-making. He used his physical experience and the medical paraphernalia of his body in his art to challenge ethnocentric notions of Britishness and position himself, and black people, as part of British history. The chapter will then turn to oral testimonies, with the second section exploring how the experiences of diagnosis, migration and inheritance intersected between the 1950s and 1970s, as individuals or families journeyed from the Caribbean and West Africa and found their understandings of themselves and their families transformed by that process. The act of migrating was, as Perry has argued, a claim to citizenship, and this experience could be embodied, as people made the journey from the Caribbean and Africa and in the process redefined their bodily experiences and their family histories. Thirdly, this chapter will turn to the relationship between families and individuals affected by SCD, and the staff and spaces of the NHS and the broader Welfare State. The staff could be

\textsuperscript{22} Perry, \textit{London is the Place for Me}, 247.
antagonists or feel like family, the spaces could be hostile or almost like home, and
patients and families could feel alienated or seen. These conditions could in turn
influence the experience of the disease’s physical symptoms, as the individual
evolved coping mechanisms to manage their illness and their lives. This thesis has
argued that Black Britons’ claims to citizenship were ‘denied, dismissed or
delegitimised by the British state’ partly through its neglect of, and disinterest in, the
bodily health of black people. This chapter argues then that people living with SCD
claimed their citizenship, in return, through their bodies and their experiences of
health and illness, as they invoked their right to care and observed the operation of
the state from the vantage point of the hospital ward.


We first met the artist Donald Rodney at the very start of this dissertation, as he
contemplated Max Perutz’s haemoglobin model in the Science Museum in London,
and pressed a button that lit up the sickle cell mutation. Despite the advancement of
genetic knowledge and the ‘mapping’ and ‘modelling’ of haemoglobin molecules –
achievements celebrated in one of the largest museums in London – little of this
could be translated into anything approaching a cure for Rodney’s illness. In
examining these models, Rodney saw his invisible illness, which he had always felt,
rather than seen, being given form. He felt not recognition, but surprise, at the
smallness and seeming insignificance of the single genetic alteration that had
shaped his life. We know about this encounter in the Science Museum because he
told the story in the 1995 film 3 Songs: Pain, Light and Time. In this film, Rodney
collaborated in making himself into an artistic subject, and inviting the viewer into his
own artistic vision. In telling this story and allowing it to be incorporated into the
mythology that circulated around him as an artist, Rodney presented an image of
himself being seen – both through the film and partially in the haemoglobin model –
but also as seeing, returning that appraising gaze in kind. As an artist who was
deeply interested in the position of Black people in British society, and as a person
who lived with SCD and spent much of his life in hospitals, medical spaces and
materials became central to his project of exploring what he saw as a sickness at the heart of Britain, dissecting state violence with the tools of medicine to lay bare the racist foundations of the state. Exploring Rodney’s artistic output offers a perspective on SCD as a lens not through which the state saw its black citizens, but through which some of its black citizens saw the state. Rodney undertook his artistic training at Bournville School of Art, Trent Polytechnic and the Slade. Between 1982 and his death in 1998 his work was featured in six solo and fifteen group exhibitions. In addition to his exhibited pieces, 48 of his sketchbooks are also held in the Tate Archive, in which he recorded his observations, developed early ideas for pieces, planned and laid out floor plans for the resultant exhibitions, and wrote routine reminders, lists, phone numbers and appointments.

Rodney became involved in the art collective the Pan-Afrikan Connection and then the BLK Art Group of the early 1980s. Stuart Hall described these groups as the second ‘wave’ of post-war Black British diaspora artists, often second-generation men and women who were ‘the first black generation to be born in the diaspora’. Rodney counted the artists Keith Piper, Sonia Boyce and Lubaina Himid among his contemporaries.

Hall became increasingly interested in the Black British arts movement in later life, explaining that this art was the theorizing he had dedicated much of his career to, but applied and made ‘concrete’. ‘[B]ecause of the dependence of art on the distillation, the concentration that has to take place if this is to yield a concrete object, a painting, a piece of sculpture, an installation, a film… can’t remain within the conceptual, that can’t be the principal dimension’, he explained. By way of example, Hall identified the motif of a ‘deliberate ‘staging’ of the black body’ in the work of many of these artists.

This was the black body, presented as a moving signifier – first, as an object of visibility which can at last be ‘seen’; then as a foreign body, trespassing into

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24 ‘Forty eight notebooks and sketchbooks written and created by Donald Rodney, and the personal archives of the artist’, TGA 200321, Tate Archive.
unexpected and tabooed locations; then as the site of an excavation. This is the body as a space or canvas, on which to conduct an exploration into the inner landscapes of black subjectivity; the body, also, as a point of convergence for the materialization of intersecting planes of difference – the gendered body, the sexual body, the body as subject, rather than simply the object of looking and desire.  

Hall noted the propensity of many of these artists towards portraiture and self-portraiture. Rodney frequently incorporated his selfhood and his physicality into his art, reflecting both on his own subjectivity and also on the particular ways in which he – and black men in Britain more generally – were objectified. The curator and cultural historian Mark Sealy has observed that a key theme in Rodney’s work was ‘his relationship to the body as a political space, both internally and externally’. In considering his own selfhood, and often constrained by his working conditions due to his illness, Rodney was inescapably a person with SCD. As a person whose body was routinely subject to examinations, tests, operations and medication, as he looked outward to explore the position of Black people in Britain, in British history, state and culture, his attention was also repeatedly drawn inwards. He used the records of his body to ‘excavate’ the collisions between black subjectivity and the objectification of ‘the black body’.

Rodney was born in Birmingham in 1961 and grew up in Smethwick, a town which became notorious three years later as a result of a 1964 by-election, in which the Conservative candidate Peter Griffiths took the parliamentary seat from the incumbent Labour MP in a campaign that included racist slogans. Marshall Street itself was visited by Malcolm X in February the following year, a few weeks before his assassination at a rally in New York. Smethwick had made national and international news when several of the street’s residents called for the council to buy

up empty houses to lease to white families only – Malcolm X told reporters that he was ‘disturbed by reports that coloured people are being treated badly’. Twenty years after this, the young Rodney linked his home town to apartheid South Africa, writing in a poem that ‘I listened... and heard the wailing in Soweto to Sharpeville to Smethwick’. He recalled that ‘Theres no black in the union Jack was daubed across the walls of my mothers [sic] Smethwick home.’

A draft epitaph for himself written in 1983-4 recalls that he was born in a region ‘described by urban anthropologists / as a ghetto as a / slum as a black hole’, though ten years later in Truth, Dare, Double Dare he spoke about his love for the town as well. Rodney reflected that his artistic vocation arose from the restrictions his illness imposed on his childhood. In and out of hospital throughout his youth, at school he had been in a special unit for the physically disabled. ‘I often wonder what my life would be like without pain and I certainly wouldn’t be here now,’ he reflected in 1994. ‘I wouldn’t have been pushed into doing art at school because I would have been encouraged to do sports.’ He spent his foundation year at Bournville School of Art as a ‘flower painter’, and had arrived at Nottingham Trent wanting to be ‘the black Picasso’. But there, meeting Keith Piper and Eddie Chambers, who were making art about being black, prompted a change of course. ‘I thought, I should start doing things about me’, he later recalled. ‘It might seem like a huge jump, but it was a radicalisation process, I suddenly became aware of what I wanted to say and who I wanted to say it to’.

Between 1982 and 1988, Rodney made a series of paintings and mixed-media compositions, often dealing with histories of slavery and colonialism, often combining text and imagery. By the late 1980s, he had increasingly begun to incorporate sculpture into his works, as in 1987 with The House that Jack Built, and

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31 Donald Rodney, ‘Sketchbook no 2’, 1982-5, Tate Britain archive.
32 Ibid.
33 Donald Rodney, ‘Sketchbook no 3’, 1983-4, Tate Britain archive.
37 See Rodney’s works 100% Cotton, The South’s Favourite Cloth, How The West Was Won and Sadly, The Redskin Has His Reservations (all 1982).
to figure paraphernalia from his illness and hospital stays into his work. Eddie Chambers observed that Rodney always maintained a ‘critical distance’ between his work and his illness. Indeed, by consulting the archives left behind by Rodney, we can learn little about his experience and thoughts on SCD specifically. Instead he used the condition as a shifting metaphor for the ‘inheritance’ of black people in Britain – the medicalisation of the black body, the pathologisation of black masculinity, and the paradox of living in a country with a long history of enslavement and exclusion of black people. In practice, however, Rodney made his art sometimes literally from the hospital bed. His partner Diane Symons recalled that ‘Donald would always carry a sketchbook. When he was going into hospital, and sometimes if we’d called an ambulance at 3, 4 in the morning, he would make sure that he had his sketchbooks with him, and he would work on the sketchbooks throughout his hospital stays’.  

Within the sketchbooks, among plans for exhibitions and artworks, Rodney sketched the everyday objects and people of the hospital – blood bags, X-rays, nurses. To the film 3 Songs, he contributed Super 8 footage he had taken during his hospital stays – grainy shots of doctors and nurses changing his IV tubes or his bedding. He became the auteur of his own hospital experiences, inverting the doctor-patient relationship by making notes on the medical process from his own bed, and by incorporating the material culture of the hospital into his art. Rodney claimed power by documenting and making meaning from his experience within the hospital. Tellingly, he wrote in his first notebook from 1982 that:

Pathology an interesting detecting prosses that examines the dead body and things to find out why it got that way.  
The role of the black artist is both populist polemisis [sic] and confrontational technician.

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40 Sketchbooks no 1 and 37, Tate Britain archive.
Living in a body that was closely examined, monitored and medicated, Rodney returned this clinical gaze in kind. Sometimes in hospital for months at a time, his illness shaped his artistic method, and influenced the way his art was perceived. By picking out the way SCD was threaded into the political critiques of his work, we can identify the way SCD was staged in relation to the state.

In his 1988 piece entitled *Self-Portrait: Policing the Black Community, Death in the City: Mr Winston Rose, Mr Stephen Bogle and Mr Clinton McCurbin – a Postmodern Postmortem*, Rodney articulated a complex argument about the slippage between the care and control of black men by the British state. McCurbin died during his arrest for shoplifting, Rose died in a police van while being detained under the Mental Health Act, and Stephen Bogle died due to lack of care during a sickle cell crisis (see Chapter 2). The title was ‘policing the black community’, and yet though two of these men had entered police custody because they were deemed to be in need of medical attention, they died. In describing it as a self-portrait, Rodney placed himself in the picture alongside the three young men of the title. In another work also described as a self-portrait – *Self-Portrait: Black Men Public Enemy*, Rodney presented photographs of black men with their eyes obscured by anonymizing black rectangles. He intended these images to represent ‘generic black men, a group of faces that represented in a stereotypical way black man as the other’, black man as the enemy within the body politic. He drew these images from the *Sunday Times*, the *Evening Standard*, and he said – ‘a book on blood diseases’. By collapsing these separate images into one composite, Rodney made the point that no matter the situation, even if the man in question was gravely ill, the police could only see the generic face of the black man as a physical threat, entitled not to the state’s care but to its control. His inclusion of an image of a black man from ‘a book on blood diseases’ also hints that medicine is equally capable as media in objectifying black people.

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Rodney elaborated on these themes in his ‘Britannia Hospital’ series. Also produced in 1988, this series referenced a 1982 satirical film which sought to critique contemporary British society through the metaphor of an NHS hospital. In one painting from the series, Britannia Hospital III, Rodney depicted a black patient lying in pain on a hospital bed, flanked by two faces of the British state – a white police officer and a black nurse. The police officer, who turns unseeing away from the ailing patient, is from the Special Patrol Group. The SPG gained notoriety after they killed the protestor Blair Peach in 1979, and their presence in this piece is a symbol of the increased powers that the Conservative government had bestowed upon the police following the 1981 riots, particularly in the crowd control technologies that the SPG specialised in.\(^43\) In the words of Rodney’s friend Eddie Chambers, they ‘resembled, at times, more an occupying paramilitary force than a public service ready to serve diverse communities of British people’.\(^44\) On the patient’s other side, he is being tended to by a black nurse. It is striking that Rodney – who had spent much of his life in and out of hospitals – chose a black nurse to be the face of British medical care. In Britannia Hospital III she is a quietly radical figure attempting to care for the patient, reflecting the large proportion of the NHS’s nursing profession made up by black nurses, and possibly the role they specifically played in intervening on behalf of SCD patients.\(^45\) In the far left corner of the painting is a black women held in a harness, her body open and exposing a fragile and broken column. A reference to Frida Kahlo’s self-portrait The Broken Column, this figure made visible not the invisible pain of Rodney’s sickle cell disease but the pain and damage inflicted by institutional racism in 1980s Britain. This work revealed to the viewer, in Hall’s words, ‘the stubborn persistence of racial thinking as part of the deep, unconscious structure of British common sense, often crystallized in institutional cultures’.\(^46\)

In this work, Rodney told the viewer about his own experience of ‘Britannia Hospital’ only through his chosen medium. The progressive damage of his sickle cell anaemia had severely limited his mobility by this time, and increased his periods in

Fig. 7: Donald Gladstone Rodney, Britannia Hospital III (1988) oil on canvas, pastel on X-ray © The Estate of Donald Rodney, Courtesy Museums Sheffield.

The Estate of Donald Rodney, Courtesy Museums Sheffield.
hospital. He used x-rays of his own body as panels on which he could work small scale, whilst seated, and which could then be assembled into the final image. Chambers argues that the use of Rodney’s body was not intended to centre Rodney or his disease, but to suggest that

just as a surgeon could see disease and decay in a body through the use of X-rays, similarly – through a potent combination of historical and ongoing societal experiences – black people saw societal disease that white people refused or were unable to see.\(^{47}\)

The biography of Rodney on the posthumous Autoicon CD-ROM that a small group of his friends and collaborators made about him and his work declared that ‘Donald used X-rays as a metaphor to represent the ‘disease’ of apartheid, the ‘disease’ of police brutality and the ‘disease’ of racism that lay at the core of society’.\(^{48}\) In his own reflections about SCD, Rodney expressed frustration about the limitations his illness placed on his life and his artistic ambitions, saying longingly ‘I wish I had the luxury to work in a studio’.\(^{49}\) Though the video portrait of Rodney was titled Three Songs: Pain, Light and Time, Rodney reflected in it that ‘I don’t think I’m able to turn the experience of pain into art very well, not physical pain anyway because it’s so difficult… I prefer to turn psychological pain into art because it’s a bit easier’.\(^{50}\)

By the 1990s Rodney increasingly incorporated not just medical instruments but the material of his own body in his art and installations. In 1990 he made Visceral Canker, a ‘bold and thoughtful attempt to animate several key issues relating to Britain’s historical involvement with the Atlantic Slave Trade’, as part of a project for the TSWA (Television South West Arts) Four Cities Project.\(^{51}\) Displayed in the

\(^{47}\) Chambers, ‘Who’d a Thought It?’, 24.

\(^{48}\) Elements of the original autoicon CD-ROM are preserved at ‘autoicon’, i-DAT website, https://i-dat.org/autoicon/

\(^{49}\) The 1994 sound installation Truth, Dare, Double Dare is the joint property of the Estate of Rose Finn-Kelcey and the Estate of Donald Rodney. I heard and transcribed this audio at an event: ‘On Allyship (BSL Interpreted)’, Institute of Contemporary Art (11 June 2019), https://ica.art/live/on-allyship-bsl-interpreted


disused Mount Edgcumbe gun battery in Plymouth, the work featured two large coats of arms embossed upon wooden panels: those of Elizabeth I and those of Sir John Hawkins, a native of Plymouth and the first English slave trader. In Rodney’s words, ‘because of his dealings with slaves Queen Elizabeth I granted [Hawkins] the ability to change his coat of arms’, and he chose ‘a demi-Moor proper bound captive’ and ‘three Black men shackled with slave collars’ to adorn his new emblem.\(^5^2\) Elizabeth I in 1596 had also ordered the expulsion of ‘blackamoors’ from the British realm. Chambers interpreted Rodney’s work as giving ‘graphic visual form to an historical unholy alliance that both sanctioned the enslaving of Black people and sought to regard them as a foreign, alien and wholly undesirable part of the sixteenth century [sic] population of Britain’.\(^5^3\) Rodney linked these two coats of arms by plastic tubing mimicking intravenous therapy lines, pumping Rodney’s own blood around and between them. Or rather, it was meant to be Rodney’s own blood – as it turned out, Rodney recalled,

> Everything was going well until somehow the council found out I was going to be using my own blood and that I had a disease, and so at the time you know all this hysteria about blood-borne diseases they thought, anyone with a blood disease had to be AIDS, or had to be something that was incredibly contagious, so they refused to have the piece put up. So what we did instead was to use theatrical blood, and we’ve had to do it twice now because of them, and I’m getting a bit peeved because of it because I never get a chance to do what I want to do.\(^5^4\)

Rodney’s frustration illustrates how important it was for him to locate himself physically within these histories. Rodney was the Black British son of Jamaican parents, descended from those enslaved by the British and now living on the island from which Elizabeth I had attempted to expunge black people. This blood, Rodney

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wrote, ‘serves as an analogue for all Black blood, or all Black people, who are frequently seen as a cancer within white society’. In the audio recording *Truth Dare Double Dare* he made four years later with Rose Finn-Kelcey, Rodney reflected that ‘my blood is my major enemy’ because he felt it to be destroying him from the inside. In this work, the slippages created between his own body and the body politic, and between the internal and external political space of the body, we come face to face with (in Stuart Hall’s words) ‘not with some essential ‘truth’ about blackness, but with… the end of the essential black subject… triggering a kaleidoscopic proliferation of meanings around blackness’. By placing these elements in circulation with one another, Rodney invited reflection on the contradictions and tensions at the heart of Black British identity. The work also drew back the veil on the source of the invisible pain that Rodney described as his ‘constant companion’, though made it no more visible. Rodney wanted the materiality of his own ‘blk blood disease’ (as he described it in one of his notebooks) which shaped his own creative process to be represented, literally, in his art. The plastic tubing also represented the blood transfusions that were a frequent feature of his life. That Plymouth council refused the use of Rodney’s own blood for fear of ‘unnecessary offense to public sensibility’ and health and safety concerns was reported in the media, and Rodney included this detail when the piece went on tour to New York. This censorship became part of the story told around the work, and added another layer of meaning to it – illustrating that Rodney’s body was understood by authorities as a threat.

Rodney’s friend Virginia Nimarkoh argues that Rodney used ‘his own physicality’ – which incorporated of course his illness and disability – ‘as a metaphor to critique Black masculinity’. He reflected in *Three Songs* that ‘More and more my work is dealing with black sexuality, black male masculinity, because it’s there all the time, black masculinity intrigues me because being a black man and constantly being told that I am a threat, and being constantly told that I am this, I am that,

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56 *Truth, Dare, Double Dare* see footnote 48.
Fig. 8: Donald Rodney, *Visceral Canker* (1 panel, 1990), perspex, wood, silicon tubing, gold leaf, plastic bags and electrical pump © The Estate of Donald Rodney, Courtesy Tate Britain.
makes me wonder about it a great deal.' As he spoke, he was shown on screen walking down some steps with a cane. As a black man with a serious illness (he registered as disabled in the mid-1990s but his mobility had been severely limited at different points in his life), Rodney observed the double-edged stereotype of black male virility, strength and aggression, particularly in media representation. In his 1992 piece *Doublethink*, he assembled a collection of cheap sporting trophies on shelves and in cabinets, with plaques bearing ‘half-truths and lies’ about black people, including ‘the role models set by black men are poor and black boys end up floundering’ and ‘black sportsmen have poor IQs’. This ‘doublethink’ of the title was the fetishization of black ‘sporting prowess’ accompanied by the denigration of black men, women, culture and family, and Rodney observed in the exhibition catalogue that ‘[a] black sportsman can receive both cheers of appreciation and taunts of racial abuse. This truism is entrenched into the contemporary fabric of black life’.59

In his piece *Flesh of My Flesh* (1996), Rodney and the artist Rose Finn-Kelcey juxtaposed photographs of a strand of each of their hair. Nimarkoh writes that Rodney’s plan had been to ‘expose stereotypical notions of the Black male (crude, thick, rough, dark) versus those of the White female (delicate, smooth, fine, blonde), by photographing the hairs under an electron microscope’ and found that ‘at such close proximity, visual difference is indistinguishable’.60 Rodney and Finn-Kelcey’s working relationship had been fraught, and their joint work *Truth, Dare, Double Dare* – an audio recording in which each voiced their frank thoughts about the other – suggests that each resented the other partly for their divided identities. He was a man, she a woman; he was black, she white; he was disabled and wheelchair-bound, she was able-bodied and mobile. In this context, *Flesh of My Flesh* reads as an effort to resolve these differences through a molecular comparison. But although the photographs are nearly identical, any possible message of unity or commonality from the composition is undermined by a central photograph of Rodney’s scar, which links (or divides) the two. Nimarkoh remarks that ‘by medical standards the scar was exceptionally poor in the sense that it was evidence of malpractice: over-stitching by

60 Nimarkoh, ‘Image of Pain’, 86.
Fig. 9: Donald Rodney, *Flesh of My Flesh* (1996), photograph on aluminium. © The Estate of Donald Rodney. Courtesy the South London Gallery.
a reckless surgeon who apparently felt that Black skin was ‘tougher’ than White
skin.” 61 Though the Biblical phrase ‘flesh of my flesh’ refers to the creation of Eve
from Adam’s rib, Rodney locates the rupture between him and Finn-Kelcey not in
gender but in ‘race’. While the hairs testify to the absence of any biological
foundation for ‘race’, Rodney’s scar bears witness to its social reality, in terms of the
values attributed to skin colour and the resultant injury visited upon, in particular,
black bodies and psyches by institutional and individual racism. *Flesh of My Flesh*,
after being displayed at the Barbican, went on tour to hospitals around Britain. But at
St Bartholomew’s Hospital in London, the piece was displayed in a non-public area,
for the reason that ‘the image of the artist’s scar might offend patients and visitors’. 62
In this period, suffering from intense ill-health and having spent six months in
hospital shortly before, Rodney was attempting to portray his physical pain through
the depiction of his scar. In St. Bartholomew’s discomfort with the image of Rodney’s
pain, there are echoes of the experiences of other patients with SCD – particularly
those who were scolded for crying out in pain and disturbing other patients, but not
provided with adequate pain relief.

Throughout his career, Rodney’s person and his art were perceived by
others through the prism of his illness. Many of his reviewers responded to the
apparent symbolism of his illness, as an artist suffering from a ‘black disease’ who
sought to critique the race politics of Britain. In 1988, the art magazine 20/20 literally
announced his death in an article about his new show. Recalling this
misunderstanding after Rodney’s death aged 37 on 4 March 1998, Mike Phillips and
Geoff Cox wrote that ‘Rodney was not dead but dying, the premature announcement
predicted the inevitable result of a Darwinian curse which has afflicted Rodney since
childhood’. 63 Even in critiquing this perception of Rodney as somehow living under
the shadow of death, they repeated it. This tension between his dual identities as
artist and patient emerges in much that has been written about him. The text of his
*Autoicon* CD-ROM, authored by his friends and collaborators, argued that ‘[w]hilst he

61 Ibid, 86.
62 Ibid, 89.
Magnanin, 1998).
could not escape or conquer his sickle-cell, he refused to declare himself a victim of it. His use of X-rays was not to draw attention to the blood disorder that was slowly corroding his body'.

In his essay on Rodney’s corpus, fellow artist and friend Eddie Chambers variously emphasised that ‘Rodney steadfastly refused to invoke pity or sympathy within his work’, that he ‘refused to position himself as a victim and use his illness as a prop for his art’ and ‘steadfastly refused to declare himself a victim of it’. Chambers contrasted this attitude with the contemporary art of the late 1980s and the early 1990s, in which HIV/AIDS emerged as a highly politicised and stigmatised health condition. ‘Many artists who were AIDS sufferers, or who were HIV positive,’ Chambers wrote, ‘eagerly seized new opportunities to make work in which they declared themselves to be righteous sufferers and oppressed victims of society’s and the establishment’s apparent indifference to their plight’. As Chambers put it, ‘[i]t would have been easy for Rodney to appropriate this new and politely received culture of victimology by exploiting his sickle cell anaemia within his artwork’. SCA had an existing social narrative and image that Rodney could have tapped into through visual, artistic tropes. Chambers outlined this narrative thus:

according to the culture of victimology, because only Black people are affected by it, the government, the medical profession and the nation at large accord sickle cell scant recognition. So those who suffer from sickle cell become justifiably aggrieved and abused barometers of racial justice, particularly at a time of ‘tolerant Britain’ in which Black people are widely perceived as having benefited from equal rights and equal opportunities policies.

Rodney, Chambers emphasises, did illness within artistic practice the ‘right’ way – treating the illness as an access point onto broader social narratives about race, identity and pain, rather than a subject in and of itself. Implicit is that Rodney was a

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65 Chambers, ‘The Art of Donald Rodney’, 32, 33
66 Ibid, 30.
valid patient, because he did not centre his health in his art but the bigger issues of race and racism.

A central theme in Rose Finn-Kelcey’s bitter criticism of Rodney in *Truth, Dare, Double Dare* was what she saw as his use of his illness to avoid responsibility in their working relationship. The statements or feelings she expressed about Donald on the audio recording included ‘Donald’s illness is his site of manipulation’ and ‘Pain excuses Donald’. She resentfully referenced Donald’s friends’ insistence that he ‘had never used his illness as a tool of manipulation’. In these tales there is a sense of pressure from within the artistic community – even his close friends and collaborators – to relate to his illness in certain, prescribed ways. In avoiding martyrdom, he was martyred – as a disabled artist who did not centre his disability in his art. Rodney himself, in his own reflections about his illness, discussed the practicalities and limitations it imposed on his life, reflecting in his part of *Truth, Dare* that ‘I fear the thought of getting back to the hospital’ but also that he felt neither good nor bad about hospitals in themselves. In *Three Songs* he explained that ‘within the black community and the art world as well you do become partly invisible because of having a disability’. His work in the 1990s, including *Flesh of my Flesh* but also *Psalms* – an empty, motorized wheelchair that moved around a display space, made when Rodney was too unwell to come to his own opening – increasingly took disability as their subject. Virginia Nimarkoh – also a friend of Rodney’s – sees his work as centring the body, and forming part of a broader shift in the mid-1990s towards the emergent genre of ‘body art’. She cites other practitioners of such art in this period, including Jo Spence, who documented her experience with breast cancer throughout the 1980s and 1990s with stark and intimate photography of her body, and Mona Hatoum’s video installation of an endoscopy of her body. Discussing *Flesh of My Flesh*, Nimarkoh argues that ‘[i]n order to subvert the construct of the black victim, Donald turns to the source of his own pain – his body’.

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68 *Truth, Dare, Double Dare*. See footnote 48.


and that his frank and unsentimental depiction of his scar meant (in the words of James Baldwin) that he ‘ceased to be a victim’ but has ‘become a threat’.

On the last page of his final sketchbook, in 1998, Rodney reflected not on death, but on his developing artistic practice:

> Perhaps I should stop making art that is so so loaded with critical political insight. Perhaps [sic] I should try to look at the ordinary the mundane and challenge the human aspects in all of us. Beauty love fear hate color and joy. Mistakes and life as we live it with all its complexities and contradictions. Art and its day to day relationships its umbelical connection to our existence… I should look at the universal, searching the avenus [sic] that art and artists have explored through time, subjects as wide and full of scope as life, death, love, hate and fear and loathing.

Rodney had been described as ‘not dead but dying’ by his fellow artists, but these words – his last words for the historical archive – tell us that he was very much living and thirsting for more life, with all its ‘complexities and contradictions’. His was – like all of those who have died from SCD – a life cut short, and the world he left has been deprived of the new artistic phase that this sketchbook entry might have heralded.

Much of the comment on Rodney has stressed that, because he did not define himself through his disease, he was unlike other artists – that his refusal to see himself as a ‘victim’ of his disease made his art great. But this assessment misses the ‘complexities and contradictions’ in Rodney’s life. He was reflective on how his illness shaped his life as an artist – it kept him indoors as a child, drawing rather than playing sport, and imposed physical limitations which he worked creatively to navigate. He wrote his illness and his body into his art – to repeat Stuart Hall, Rodney used his body as ‘a space or canvas, on which to conduct an exploration into the inner landscapes of black subjectivity… as a point of convergence for the materialization of intersecting planes of difference’. Rodney was the subject, not

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71 Ibid, 89-90.
72 Donald Rodney, ‘Sketchbook no 48’, Sketchbooks and artwork TGA 200321/3, Personal archives of Donald Rodney, Tate Britain archive.
the object, as he staged his own body in a precise and analytical way. From his studio and his hospital bed, he turned the medical gaze back on itself – using the tools of medicine to physically situate himself (through the use of X-rays and blood) in British history and its body politic. Rodney’s work illustrates the cultural symbolism of SCD during the 1980s and 1990s as a symbol of, and an analytical access point onto, insidious British racism. He was not a ‘victim’ – he was the one watching and analysing. He was not ‘dying’ – the work that he made lives on.

Migration, family and ‘moments of truth’, 1960-2019

Policymakers and doctors in Britain long assumed that, among the Windrush generation of migrants from the Commonwealth, there could not be individuals with sickle cell disease. The disease, it was believed, was so severe that – in the words of a 1970 article in the *British Dental Journal* – ‘not many [sickle cell disease] patients survive to adult life’, let alone undertook the journey to Britain.74 Bivins notes that both the MRC and DHSS and their medical and scientific advisors ‘assumed that homozygous individuals died in childhood or in very early adulthood’, and as such services for adult sufferers and trait carriers were completely ignored.75 This assumption may partly account for the scarcity of archival records of the experiences of individuals with sickle cell disease in Britain before the late 1970s. Accordingly, although the dates of my thesis span between 1948 and 1997, almost nothing has been written about the experiences of individuals with sickle cell disease in those first two decades. In this context, oral history has proven an invaluable tool of analysis.

Although my interviewees were primarily second-generation, several of them had first-generation parents or other relatives with forms of sickle cell disease, who arrived in the 1950s or 60s. As a result, experiences of sickle cell disease from these lost decades are partially accessible through family histories, and in this section I will discuss what these can tell us about migrant experience and contact with the new

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75 Bivins, *Contagious Communities*, 331.
NHS. Susan Lindee’s 2005 work *Moments of Truth in Genetic Medicine* explores encounters between American genetic researchers and communities affected by genetic disease, such as an Amish community in Pennsylvania affected by dwarfism during the 1950s, and a New York Ashkenazi Jewish community affected by familial dysautonomia. Lindee focuses on how lived knowledge of illness passed on in families could combine with technical knowledge to produce ‘moments of truth’, which she describes as ‘a moment of recognition or understanding, the moment when a given narrative can be classified or categorized and placed in a narrative that explains it’. This concept of ‘moments of truth’ is complicated in the context of postwar Britain, when that encounter was between migrants from the Commonwealth and NHS physicians. As some individuals and families moved back and forth between Britain and their countries of origin, this process of migration became incorporated into their family histories, sometimes disrupting their conceptions of family history or reframing their physical experiences. These ‘moments of truth’ might also be seen as ‘epiphanies’, which Lynn Abrams argues reflect a ‘cathartic reconstruction of the self’ as narrators seek to reconcile changing social expectations in their experiences with a need for a ‘coherent, acceptable and constantly revised life story’. Anne Hunsaker Hawkins has argued that epiphanic thinking in medicine is most recognizable in the act of diagnosis, as symptom patterns come into focus.

Moments of diagnosis often surfaced as epiphanic moments of truth in these oral histories. Suzanne’s mother, Heather, migrated from Grenada to London in the mid-1950s. Suzanne remarked that, when Heather was growing up in Grenada,

She’d have recurrent episodes of pain, but she just learned to deal with it, cos in Grenada, you can’t see a doctor, you can’t afford it! … I now realise she’d had recurrent crises.

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Heather’s mother had attributed these pains to unripe mangoes, and Heather’s brother would rub her stomach with kerosene oil, which Suzanne described as having had a ‘placebo effect’ because ‘she was really close to her older brother’. Heather was only diagnosed with sickle cell disease in the UK, when she became pregnant and experienced complications with her pregnancy. Travel from Grenada to Britain – where she was able to see a doctor for free – reframed the aches and pains that Heather had previously understood as related to her diet, while the physical distance separated Heather from a relationship with her brother which Suzanne described as physically healing. Heather’s early years in ignorance of her condition may have influenced her future approach to its management. Suzanne recalled her mother’s remedies to their shared illness as a warm bed and hot, sweet coffee, as opposed to the long waiting times and ineffective treatments at London A&E clinics. While the NHS had offered diagnosis, the treatment options it provided were limited. In our interview, Suzanne – a trained doctor who also lives with sickle cell disease – interpreted her mother’s experience through her understanding of crisis, and imagined the moment in which Heather’s blood was examined ‘under the microscope’ where, she says, ‘they saw it’. Suzanne’s vivid description of this moment of discovery, of doctors viewing sickled cells under the microscope, is suggestive of discussions between her and Heather about Heather’s diagnosis, which in turn led to Suzanne’s diagnosis. This ‘moment of truth’ is framed through her own subsequent medical training.

Helen’s parents came from Domenica in the early 1960s. Helen recalled what [my mother] told me was that whenever she had children she was fairly ill… I think in the Caribbean you have aches and pains, but they have their own little medicinal things, they boil bush, they do x, y and z… there was little things she thought ‘oh, maybe that was why’ but they were not huge, not massive things.

Helen’s mother was diagnosed with a variant of sickle cell only when Helen, then aged three, was diagnosed with sickle cell disease in a hospital in North London.

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79 Suzanne (pseudonym), interview with GR, 16 April 2018.
Helen’s mother was told by NHS doctors not to have any more children because of the risk that they would have sickle cell disease. She refused, but Helen said that later in life, when the severity of her condition became apparent, her mother apologized to her for having given her sickle cell disease, and asked if she blamed her for her illness. Helen’s father, on the other hand, refused his diagnosis as a trait carrier. ‘They both had to be carriers,’ Helen told me, ‘which my father denied, even up to the day that my dad passed away he still denied that he was a carrier, even if he had a blood test and it proved he was a carrier, he still was like ‘Nope’.’ Helen’s parents contested the message of ‘technical knowledge’ from NHS doctors. In Lindee’s work, members of the Amish community sometimes refused the implication that there could be genetic ‘error’, on the grounds that this implied a mistake in creation. In the context of postcolonial Britain in the 1960s, the power dynamic between a white doctor and a Black patient, complicates Lindee’s concept. The doctor’s advice to Helen’s mother reflected the widely-held notion that children with sickle cell died young – despite the fact that Helen’s mother herself was an example of this not always holding true. In the context of great medical and state scrutiny of the fertility of Caribbean and African migrants, and fears of subsequent dependency on the Welfare State, this doctor’s recommendation is particularly loaded. Helen’s parents resisted, instead trusting their own sense of themselves as a healthy couple who wanted to build a family.

Both Helen and Suzanne’s mothers were diagnosed with SCD through their experiences of motherhood – Suzanne’s mother was diagnosed when she was unwell during her pregnancy, resulting in the subsequent diagnosis of Suzanne at birth, while Helen’s mother was diagnosed following Helen’s own diagnosis. Women’s experiences of childbirth and motherhood particularly medicalized them and made their bodies a focus when families came to make sense of SCD. Meanwhile, Helen’s father rejected the notion that he could have the sickle cell trait, though he accepted absolutely that he was her father. I asked Helen how her father was able to square these two contradictory beliefs in our interview. She mused that

80 Helen (pseudonym), interview with GR, 14 August 2018.
81 Lindee, Moments of Truth, 58-89.
82 Bivins, Contagious Communities, 228.
I can't speak for him, but I don't know whether he was in denial... because he understood eventually, that both parents had to be carriers for the child to have this, and I don't know whether in his mind he felt that by him saying yes he had it, he contributed to giving me this illness that was horrendous, really... it was clear that it was him, but I think you know, Caribbean men in those days were sort of like, a macho man, and the man of the family, and ‘I couldn't possibly have this’[.]

This theme emerges consistently from interviews and written sources (see Chapter 4) and, as discussed above, has shaped the oral history evidence base itself. As Helen made clear, none of these female interviewees can ‘speak for him’ and articulate the perspectives of those men who rejected their sickle cell status. But these women’s stories make clear that though SCD is not a sex-linked genetic illness, experience of SCD was and is deeply gendered. Broader stigma around SCD also meant that, for many families, the illness was kept secret or shrouded in silence.

Julie was born in the late 1960s near Lagos in Nigeria, and moved to the UK about thirty years ago. She has the sickle cell trait, and has a daughter with sickle cell disease. Julie was from a wealthy family who had been embedded with the British establishment and had ‘worked with the colonial ‘masters’ as they call them’, she explained. My interview with Julie and the intricate social and familial networks she detailed in it had two distinct layers – her experience of past events, and her retrospective understanding of these past events. Of course these layers exist in any oral history interview, and always blur into and constitute one another, but in Julie’s testimony the disparities between them were a self-conscious part of her narrative. Over the course of our interview a theme emerged – that of the ‘reveal’ of family secrets through the diagnosis of sickle cell, a series of ‘moments of truth’ in which lived experience and technical knowledge combined to produce new insights for Julie and her relatives.

83 Helen (pseudonym), interview with GR, 14 August 2018.
84 Julie (pseudonym), interview with GR, 22 June 2018.
Julie had known SCD as a lethal condition from a young age, because her family’s pastor had two children with the illness. Julie recalled her own mother taking one of these children with her on a business trip to Malaysia to access an herbal cure she had been told about. After taking these herbs, the child had been crisis-free for five years – but ‘the next crisis she had, she died’. Julie recalled this death of such a close friend as a painful loss for her and her family. Continuing on her childhood recollections of SCD, Julie then recalled

also, about two doors away from me, my neighbour, they had a son… he died at the age of ten of sickle cell… But when he died they hid that from us. We didn’t know it was sickle cell. It was only after my sister got married into that family that we knew [he] died of sickle cell related complications as well. Because her husband told her.

These two deaths took place a few years apart, and Julie understood them as part of her childhood experience of SCD – but one was a secret that was, for her, only recently uncovered. Julie speculated that the family kept the illness a secret to protect the child’s mother, who might be ousted by her in-laws if they found she had a child with SCD – and recalled many examples of families in their wider social circle in which men had, publicly or secretly, taken second wives after the birth of a child with SCD. Julie linked this with broader tendencies to blame women for childlessness or failure to produce sons because of their disadvantaged position in society, because ‘women are the weaker sex out of the two, it’s easier to pick on the woman, as opposed to the man’. During our interview, Julie editorialised these beliefs and past events with her understanding of genetic inheritance, pointing out that it is male genetic material that determines the sex of an embryo, and that SCD has to be inherited from both parents. When discussing the parents’ support group that she runs in her local area, it is clear that the research that she has done about genetic inheritance is a crucial part of the emotional support that she provides for the other members, sometimes also women struggling with shame about their child’s

85 Julie (pseudonym), interview with GR, 22 June 2018.
illness, or who have been rejected by their husbands as a result of the diagnosis. In our interview, Julie powerfully debunked these claims, armed with educational pamphlets and videos that she had received from a British Nigerian nurse when her child was first born.

When I asked her if she had known of sickle cell in her own family, Julie began her answer by explaining that she understood her trait to have come from her mother, and told me the story of her mother’s sister, who had come to Britain in the 1960s and had three children there. She suffered a breakdown in the mid-1960s and her father, suspecting witchcraft, asked that she be brought back to the family home to receive traditional herbal medicinal treatments. She took her three children back to the family mansion, but shortly after they arrived in Nigeria, her daughter died. ‘[H]er dad came back from UK and thought oh they witchcraft my daughter,’ Julie told me. ‘[H]e never thought she died from sickle cell, ‘oh they witchcraft my daughter’, and so he took his sons away from my granddad… ‘Not gonna let you kill my sons the way you killed my daughter’.’ Julie and her cousins reinterpreted this family rupture – with its mistrustful accusations of witchcraft on both sides – forty years later, when the little girl’s brother returned to the UK. Julie remembered

he went for a test by himself, realised that he was AS, his brother was AS, their mum was AS, they were aware of that, now found out that their dad was AS as well. So he now thought mmm, that must have been that their sister was SS, out of the main family, and he went to check records of birth when his sister was born here.86

Julie explained that her cousin learned from these records that his sister had had sickle cell disease. Stories such as this, in which a mysterious and traumatic death in the family was later revealed to have been due to SCD, came up again and again in Julie’s testimony. In this one, the archives and bureaucracy of the NHS played a key role, ensuring that the technical information of genetic status could be fused with the lived experience of illness and death passed down in families. In this way the

86 Ibid.
foundations of painful family grudges – accusations of witchcraft and ill-will – could be debunked. The likelihood that the little girl had been diagnosed with SCD at birth in the 1960s is slim. As discussed elsewhere in this dissertation, pilots for neonatal screening programmes in Britain only began in 1973, and doctors and policymakers were complacent about their ability to detect SCD in children. However, the remembered discovery of these ‘records of birth’ are the ‘moment of truth’ encapsulated, in which biomedical knowledge and familial trauma could be reconciled.

Julie was a very enthusiastic interviewee and needed little prompting from me. Although she frequently referred to her own daughter’s treatment, and to the diagnosis stories of other members of her family, she did not bring up the story of her daughter’s diagnosis. After an hour, realising we had not discussed this, I asked her how her daughter had been diagnosed. Julie’s tone and demeanour changed. She spoke slowly, quietly and sadly.

[D]o you know in this country when you have a child, it is on the seventh day, you have a heel prick test it’s called…[it was] the morning of the christening, I had loads of people around me [when the nurse came]. So I took her into a room, away from people… and then she said, ‘oh I’m afraid, your daughter has got sickle cell.’ And I’m like – ‘sickle what?’

At this point in the interview, Julie began to cry, explaining that ‘It's like someone died, it's like you've lost somebody when they tell you that you have a child with sickle cell, that's how we as parents feel.’ Julie and her husband kept their daughter’s condition a secret from their immediate family for several years, fearing disapproval of their marriage. These stories of death and revelation are charged for Julie, because she fears losing her child as so many of her relatives had, and she felt judgement as a mother to a child with the condition. For her and her relatives, the lived knowledge of illness and family history combined with the technical knowledge of sickle cell inheritance and NHS records, tests and postmortems to offer a new

87 Ibid.
narrative. This narrative was a hopeful one. While Julie clearly has empathy for these parents who sometimes unknowingly lost children to sickle cell, she also takes comfort from a sense that awareness and treatment had improved. ‘You know in those days,’ she said, speaking about the discovery that her husband’s sister had also died of SCD in Britain in the 1970s, ‘the kind of medicals that you have now you didn’t have it back then, cos if they had it then, what they have now, she’d still be alive’. Julie concluded by reflecting hopefully that her daughter was ‘doing well’.  

Health visitor Lola Oni reflected that recognition of SCD in people’s family histories and social circles formed a critical part of the educational programme around SCD in Lambeth during the 1980s and 1990s. After giving talks at churches and community groups, Oni remembered, many people would tell her about a cousin, a friend or a schoolmate ‘who used to have this pain and you know, and used to cry a lot and we didn’t know what was wrong with him’. Sometimes, Oni said, people ‘started associating sickle with every kind of illness that exists’ and linked it to every unexplained death they’d known, and she would try to emphasize its specificity. But many times, she recalled people describing the exact symptoms of SCD in detail, and Oni cited Felix Konotey-Ahulu’s work linking SCD to the terms used in West Africa, such as Chwechwechwe, Nwiiwii and Nuidudui. This knowledge and recognition could enable productive and trusting relationships between black communities, voluntary organisations and medical staff. Susan Lindee’s book places emphasis on the role of patients and parents as well as doctors, scientists and technicians in the advances of genomic medicine in the twentieth century. In her conclusion, she writes that ‘people know things in ways that are not scientific but can be taken up in scientific narratives to explain natural phenomena… and their choices are critical to the enterprise’ of genomic medicine.

Migration and the NHS could play a role in the ways in which this genomic information could be incorporated – or not – into familial narratives. For Suzanne and Helen, their mothers’ understandings of themselves and their health were reframed by their migration to Britain and their experiences of childbirth and motherhood. Their

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88 Ibid.
89 Lola Oni, interview with GR, 10 April 2018.
90 Lindee, Moments of Truth in Genetic Medicine, 205.
contact with the NHS and its free services medicalised the aches and pains which had previously been assuaged, for Heather, by a social bond. For Helen’s mother, this new information came with firm instructions from NHS doctors to stop having children, which she and her husband rejected. Helen’s father wholly rejected the notion of the sickle cell trait, feeling that it did not match his own sense of physical health or, according to Helen, his masculinity. For Julie’s extended family, diagnosis and treatment of NHS in the 60s and 70s was patchy, and children with the illness sometimes did not survive. But Julie found, in the insights of genetic medicine, a framework with which she could critique the gendered stigma around SCD that she had grown up with, and hope for her own daughter’s future.

‘Home from home’?: Living with sickle cell in the British welfare state in the past and present

In Chapter 3 I discussed the experiences of people with SCD on Britain’s wards, and the emergent cultures of harm that were able to flourish in ignoring or dismissing the pain of individuals with SCD. These were, in some instances, countered by healthcare professionals who sought to understand the condition, improve its treatment, and lobby for services. I have also discussed the conflicted role of the community workers, who felt their loyalties and obligations divided between patient advocacy and the NHS that was their employer. The lifelong nature of SCD meant that many interviewees had come to know the spaces and personnel of the welfare state intimately. For many people with the condition, an NHS hospital was the site of their first memory, and some even went on to work for the NHS. How the post-war welfare state shaped and influenced the identities and relationships of British people has been the subject of scholarship for decades, often drawing upon lived experience or oral history research. Carolyn Steedman, in her 1987 book *Landscape for a Good Woman: A Story of Two Lives* about her working class upbringing in the 1950s and her relationship with her mother, reflected on how her childhood in the welfare state shaped her own sense of self. ‘It was a considerable achievement for a society to pour so much milk and so much orange juice down the throats of its children,’ she wrote.
What my mother lacked, I was given; and though vast inequalities remained between me and others of my generation, the sense that a benevolent state bestowed on me, that of my own existence and the worth of that existence – demonstrates in some degree what a fully material culture might offer in terms of physical comfort and the structures of care and affection that it symbolizes, to all its children.

Steedman’s book dealt with the stark differences between what was afforded to her as a child, and to her mother, who grew up without these ‘structures of care and affection’.91 Hilary Young et al have examined how the structures of the welfare state shaped family, identity and youth experience in the 1950s and 1960s, with working-class parents encouraging their children ‘to enjoy more adventurous lives that were not blighted by the fear of poverty’.92 Jon Lawrence and Jane Elliott have explored how individuals narrated their identities in relation to their experience of life on unemployment benefits during the 1980s, finding that they focused on their sense of work ethic to resist internalizing the stigma of receiving welfare.93 This section will explore how people with SCD and their families experienced lives lived within NHS spaces, their relationships with NHS employees, their sense of self and citizenship, and their trust (or lack thereof) in the British state.

Within SCD activist literature from the 1980s, (discussed in Chapter 4) a deep mistrust or fear of NHS spaces and personnel among patients and their families is apparent. A father whose wife died of undiagnosed SCD, before his daughter was also diagnosed with the condition, informed Elizabeth Anionwu that ‘[w]hen [my daughter] came home [from hospital] she said to me ‘Mummy died from it’. The hospital upsets them, they don’t like to talk much about their mum. They feel it is the doctors that killed her’.94 For older SCD patients, the ignorance of many of the

doctors they encountered led to a deep mistrust of medical personnel. For many patients who were familiar with the process of having a crisis, their knowledge and expectations clashed with the doctor’s lesser understanding of the illness. ‘Doctors in Casualty do not like to be told your condition by you the patient’, one young sufferer commented wryly to Anionwu. Patient representative Sharon Edwards told a Cardiff conference in 1991 that ‘[i]t is very hard, especially when a new Casualty doctor comes to put in a drip, I have very difficult veins, and I know what needle is usually used – a pink one – and when I say this there have been times a doctor has said “Don’t tell me my job I know what I am doing”’. One patient told Janet Black and Sophie Laws that

You go into casualty and they say, ‘Oh the doctor has just gone to bed’… You can see [the doctor] has just tumbled out of bed and then they begin to ask lots of questions, do X-rays etc, instead of relieving the pain. I’ve yet to get (to casualty and) a doctor say ‘all right, set up an IV dextrose saline, I’ll give it intravenously to let it get to the pain quickly, give her some oxygen’. She contrasted her ideal, imagined experience in A&E in which her needs were anticipated calmly and competently with the reality, in which the doctor was literally asleep. One mother found that she was repeatedly required to give doctors instructions on emergency care for her son, and sometimes felt she had to turn to threats.

At one time he was very severely dehydrated… I said to this casualty officer ‘If you leave him to get more dehydrated and I lose this child, I will kill you.’ After about half an hour a drip was set up… The time they would have spent treating him, I will spend telling them about sickle cell disease, what they should do.

95 Sickle Cell Society, *Pain in sickle cell disease*, 63.
97 Black and Laws, *Living with sickle cell disease*, 94.
98 Ibid, 97-8.
The intensity of some patients and families’ animus and mistrust of medical personnel was such that Elizabeth Anionwu said ‘as counsellors we were in an area of conflict, a battleground as one nurse put it… The patients would quite often vent anger on you as a member of the establishment’.  

Nurse Marjorie Ferguson observed that many patients ‘believe that health care providers treat them with contempt and resentment… and [they] develop love/hate relationships with their health care providers’. Tensions ran extremely high in this ‘battleground’ between patients and healthcare providers between the 1970s and 1980s, fuelled by a deep sense within the patient community of indifference, ignorance and contempt from the medical establishment.

Denise is the youngest of three, born to Jamaican parents living in Willesden in North London. I interviewed Denise in her family living room, with her mother Herma – now living with vascular dementia, a symptom of SCD in older people – listening to us talk from her armchair. Denise recalled that her own birth in 1971 heralded Herma’s diagnosis with SCD. Over the next few years, Herma spent more and more time in hospitals in which staff struggled to make sense of her condition, and treat her appropriately. In the early 1970s, Herma underwent a full hip replacement at Stanmore Hospital which ‘went completely wrong because they didn't realise they were meant to give her some blood during that hip replacement and she lost lots of blood and went into this coma, for weeks’. Eventually Herma was referred to the haematology ward at Central Middlesex Hospital, where she came under the care of Milica Brozović (see Chapter 3) and settled into a weekly routine – often living on the ward at CMH from Mondays to Fridays in order to receive treatment and blood transfusions, coming home for the weekend, and returning to hospital the following Monday. At times, she was in CMH for months. Denise remembered that everyone had known her mother, ‘Mrs Falconer’, because many of her mother’s friends were nurses who would stop off at her ward on their way to and from their shifts, and the haematologists Milica Brozović and Sally Davies would make sure to

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100 Marjorie Ferguson quoted in Anionwu, ‘Patient advocacy’, 42.
check on her. At this point in the interview, Herma interjected to remind us of ‘Sherlene [Rudder]!’, a health visitor closely involved with the Sickle Cell Society at that time. Denise had no memories of her mother being reluctant to return to hospital on Monday mornings, because ‘she felt safe in the hospital’. This safety was predicated on communication and contact – her treatment being explained to her, and her certainty that ‘no matter what, the next day she would see Dr Brozović or Dr Davies on that ward’.

This feeling of comfort and safety contrasts with the published and archival sources of the 1970s and 1980s described above. Denise was aware of anger felt by some in the SCD community towards the doctors who treat them, and referenced it, saying

when people are like, ‘oh this doctor did this and that’, I can’t lie and say we had that kind of experience, even though for 40 years, we’ve just been like – hospitals and nurses, doctors, and phone calls from doctors, and ‘doctor can you do this’.

Denise felt that in their lifetime’s contact with the NHS, her mother and family had always been treated well. She acknowledged that there had been mistakes in her mother’s care – particularly the mistakes that led to her coma in Stanmore – but reflected that it had not come from a lack of care or attention, but from a lack of knowledge.

It wasn't nobody's fault, it's just not a lot of people had that illness at that time. And remember this was a white country so white people didn't really have that, and then the people started to come from abroad. And then they're realising that people are not well and ‘what is this thing? I've never seen this in the blood before’, and then that's when it all sort of started.

This lack of medical familiarity with SCD seemed understandable and inevitable to Denise. I mentioned that some people from the SCA community believe the poor treatment from doctors and nurses on hospital wards was due to racism, and asked
her what she thought about that. In response, Denise told me that her parents had been very cautious in their first years in Britain. ‘[T]hey would not stay on the streets late at night,’ she said, ‘because they realised there's these skinheads out there that don't really like black people. But afterwards the racism was more about not giving jobs, trying to keep black people in poverty, and they’re still doing it now’. Framing this transition as from that of direct racism from white nationalists ‘on the streets’, to a racism in which black people were discriminated against in the job market and in a broader economic sense, Denise expressed empathy for her parents in leaving the ‘beautiful’ Caribbean for Britain, to ‘be abused by people that don’t really want you here’. She did not link this individual and structural racism to her mother’s care by doctors and nurses in British hospitals, and reflected that the treatments available and the cost of healthcare in Jamaica would have meant that ‘my mum would have been forgotten by now’.  

As children of a chronically ill parent, Denise and her brother and sister came into close contact with the NHS and the broader welfare state from an early age. When Herma was gravely ill in Stanmore Hospital, and their father was working long and late hours to support the family, Denise and her brother and sister were moved to a home in Colchester by social services, where Denise was separated from them because she was so young. ‘We were the only black children there,’ Denise’s sister Elaine remembered, ‘at the top of the house, the last to do everything’.  

Denise remembered ‘one of the kids put chewing gum in my hair, and rather than wash it out, they just cut my whole hair off’. Their father could only visit on Sundays. The experience was so traumatic that Denise remembered, on a recent coach journey, seeing a sign for Colchester and ‘it ruined my whole journey... I just felt sick’. Later on, when Herma’s condition had stabilized, Denise, Elaine and their brother were cared for by two women from social services: Mrs Griffiths, ‘who was black and she was quite big and matrony and she just roughed us up every day to go to school’, and Hazel, ‘a white young girl’ who came in the evening to get them to bed.  

Denise recalled that Hazel would try to send her to bed earlier, as the youngest, but

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101 Denise, interview with GR, 28 September 2018.  
102 Elaine, interview with GR, 28 September 2018.  
103 Denise, interview with GR, 28 September 2018.
that she, Elaine and their brother would hide together in their bedroom and lock her out. Reflecting together in our interview, the sisters observed that their experience in the Colchester home ‘set the precedent… [of] us against them’. ‘We needed to be together’, said Elaine. Denise and Elaine disagreed about their impression of Hazel, with Elaine describing her as ‘a stern stranger’ and Denise remembering her as ‘soft and loving… that’s why we treated her so badly, Mrs Griffiths we never messed around in the morning’.104

Where their experiences with social services were charged and traumatic, Denise and Elaine looked back on their memories of CMH, where they often visited Herma, with nostalgia. It became a familiar place. ‘Always, B1, B2, B3, B4 ward – C1, C2, C3 ward, we knew every part of Central Middlesex Hospital,’ Denise said. ‘When she got to D [ward], you’d know they just didn’t have any beds’. These wards at times were the setting for her relationship with her mother, who she would often visit after school. ‘We’d just talk like mother and daughter’, she said, about her day at school, church news, and gossip from the ward.105 A sense that CMH also knew them came through in the sisters’ testimony. Elaine said

For us, [Dr Brozović and Dr Davies] were like second godparents. because although they dealt with mummy they kind of took us under their wing in some way as well… They did their job, but it felt like more to us at that time… because they spoke to us, they told us, explained to us, they didn’t treat us as if we didn’t matter. Even if they didn’t realise it and it was just something they did naturally – it made a difference to us.106

Some of these encounters with these doctors were under serious circumstances in which Elaine, Denise and their brother were removed from school because Herma was critically ill. As Elaine makes clear, she felt that her family were provided with emotional care by the medical personnel who dealt with her mother. As she says,

104 Denise and Elaine, interview with GR, 28 September 2018.
105 Denise, interview with GR, 28 September 2018.
106 Elaine, interview with GR, 28 September 2018.
‘they didn’t treat us as if we didn’t matter’ – implicitly, their engagement with her made her feel like she mattered.

Helen also remembered as a child with SCD in hospital during the 1970s that one of her doctors looked after me like I was his child. That's how I felt, you know when I was hospitalised, and I was really ill and, a lot of the times when I was being given the fifty-fifty chances, they didn't realise that I could hear them saying this, and he would ask me: what would I like, I can have anything, what would I like? And I would say ooh I'd really like a nice big television so I can watch all my programmes, and he would get a television for me… [the children's ward] felt like home from home – they made me feel I was home from home.

But when Helen reached 18 in the early 1980s, she was sent instead to an adult ward in the same hospital. There, she said, she received dramatically different treatment, which she described repeatedly as ‘a nightmare’. She reflected on how growing older changed how she was seen by healthcare professionals, saying they ‘think you're an adult, you should be able to control it, that was the number one thing.’ Commonly, Helen’s requests for more pain relief aroused the suspicion of the nurse. She recalled that after going on the adult ward, her experience of her crises changed and became ‘more dramatic, they were more severe’. It is possible that Helen’s experience of medical scepticism, the impossibility of expressing pain within the hospital ward, and the intensification of her pain may have been related. She had found as a child that excitement and stress could trigger a crisis. Recent literature has attempted to reconcile neuroscience and the history of emotions, and Naomi Eisenberger has shown that social exclusion carries similar neural affective responses to the feeling of being physically injured.

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107 Helen (pseudonym), interview with GR, 14 August 2018.
Although Helen had been told to manage and suppress her expressions of pain and feeling on the ward, she linked these experiences on the adult ward to a coming to consciousness, as she began to advocate for herself.

As an adult, you become a little bit more verbal, and you become aware of your surroundings, and you become aware of your being told, stop shouting, and you're being shouted at, then you don't take it sitting down lightly, and being quiet, you respond!

Helen did not say that she felt her treatment to have been borne of racism. She explained that she felt there were two types of nurses: those who were ‘empathetic’ and for whom nursing was ‘their calling’, and those for whom nursing is just ‘money and a career’. I asked her if she felt this was an ‘innate empathy’, and though she initially agreed she then hesitated and said, ‘[a]lthough – there were many nurses, or a few nurses, who were quite harsh with me, but I did say when I was in pain, 'you're a nurse, you shouldn't be a nurse', and we became best friends after me explaining, 'You're horrible'”. After these encounters, in which she challenged her nurses’ professionalism, Helen said ‘[t]hey apologised, they said sorry… I would come on the ward and they'd treat me totally differently… I probably… touched them, for them to realise 'Oh my god, I shouldn't have treated her that way,' or 'I shouldn't have done that, she genuinely is in pain'”. Helen’s protests against rough treatment and lack of pain relief were couched in a criticism of these nurses as health professionals and articulated her entitlement to, and expectation of, care. She felt that her honesty had awakened an empathy in these nurses, and transformed their relationship into one between equals, that of ‘best friends’.109

Suzanne, like many people with SCD, remembers her early experiences of the NHS as formative for her. ‘[T]he first time I said, I want to do medicine, I was actually in hospital in Hoxton,’ she said. ‘I said, mum when I grow up I'm going to be like that man in a white coat and heal all the children in the hospital… I’d been in the NHS environment so long, in and out of the hospital all the time, it was just the natural environment for me’. She undertook her medical training between 1981 and

109 Helen (pseudonym), interview with GR, 14 August 2018.
1987, and her experience pieces together a contradictory snapshot of how sickle cell was understood by British healthcare professionals at that time. She kept her illness a secret from her fellow students and colleagues for years, never taking a day off sick, and broke her silence when she confided in the GP who was physically examining her before she started her clinical training in 1984. Suzanne recalled that ‘he said ‘oh you should not have been allowed into medical school, you shouldn’t be here, we’ll have to tell the Dean, you’re really not supposed to be here.” She suggested that he was unaware of the variability of the disease, which could affect some people ‘severely, but not everyone’. Although Suzanne was allowed to continue her training, years later she had an offer of a GP partnership withdrawn when her supervisor disclosed Suzanne’s disease in her reference. Although the only impact of her disease on her work was one day off a month for a blood transfusion, she said that the image of the sickle cell patient as someone ‘in and out of the hospital all the time’ worried her would-be employers.\footnote{Suzanne (pseudonym), interview with GR, 16 April 2018.} Between these two events in 1984 and the late 1990s, the 1995 Disability Discrimination Act had made discrimination against people in respect to their disabilities in relation to their employment unlawful.\footnote{National Disability Council, \textit{Disability Discrimination Act 1995: Code of Practice, Rights of Access, Goods, Facilities, Services and Premises} (London: Stationery Office, 1999).} It is apparent that the label ‘sickle cell disease’ evoked images of disability extreme enough for her to be considered unsuitable for a career in medicine by her colleagues. Yet, both in her own experience as a child in the 1960s and in her observations as a junior doctor during the 1980s, she found healthcare professionals also tended to underestimate the seriousness of sickle cell disease and the pain associated with crises. Suzanne recalled that as a child,

\begin{quote}
When I was really young [the doctors] didn’t know about [sickle cell], so you’d be rolling in pain, you’d go to A&E, they’d put you to sit in A&E, you’d be rolling in pain for hours, and then when you got seen you were just given like routine painkillers because they didn’t realise how severe the pain was.
\end{quote}
In such instances, she recalled her mother would usually take her home, because ‘at least if you’re at home you’re in a warm bed, instead of a wooden bench in A&E’. During her medical training she remembered a lecture which confused SCD with chronic anaemia, and said that people with the condition were often unaware that they had it. ‘Did they ask us?’ she said sardonically. This misinformation and underestimation about SCD took its toll in medical expertise, and during her paediatrics rotation in 1985, Suzanne saw children in sickle cell crisis dying from pulmonary crisis as they waited to be seen, because of a medical attitude that SCD was not ‘serious’.\textsuperscript{112} What are we to make of this disconnect between her fellow doctors’ reactions to this illness when discovered in a colleague, versus their treatment of patients who presented with it? Within British medical spaces it appears that the meaning of sickle cell disease migrated and shifted: when it came to Suzanne’s own employment prospects, as she attempted to become a doctor, sickle cell was a disabling condition that would prevent her from doing her job. However, when it came to patients presenting at A&E in crisis, or requiring pain relief, the seriousness of sickle cell disease receded from view. Considered neither sick enough to be entitled to treatment, nor well enough to do the treating, Suzanne found hospitals to be a fragile home for her illness.

This split in understanding the condition to be both life-threatening and trivial was also present in Suzanne’s own thinking. Though she remembered the pain of her sickle cell crises as a child, and the paltry analgesics she received to treat it, when I asked her about the present position of sickle cell treatment she was disapproving of what she sees sickle cell patients receiving today.

\[N\]ow you sneeze and they put you on a morphine drip straightaway… they have all these nurse counsellors, ‘oh you poor little dear you must be really sad, here have DLA [Disability Living Allowance], have sickness benefit’ – me and my mum, we were horrified. My mum wouldn’t accept state benefit for anything, it was work, you went to work!\textsuperscript{113}

\textsuperscript{112} Suzanne (pseudonym), interview with GR, 16 April 2018.
\textsuperscript{113} Suzanne (pseudonym), interview with GR, 16 April 2018.
This horror of accepting benefits, combined with Suzanne’s awareness of the racism that worked against herself and her mother in their workplaces, rejects tropes of immigrants as ‘benefit scroungers’ that were widespread in the 1960s, and of the later Thatcherite rhetoric against ‘dependency on the welfare state’.

Suzanne shifted quickly from pain relief to sickness benefit, implying that analgesia and financial support from the state are analogous. In her experience, work and pain were closely related. Her devotion to work continued into medical school. ‘[N]o matter how bad the pain was during the night, my mum would just make the coffee extra strong and extra sweet and I’d put the matchsticks in, so I never really had time off.’ After the scare of her encounter with the doctor who told her ‘you’re not supposed to be here’, she said ‘I just doubled the effort’ in order to stay in medical school. Even now, Suzanne tries not to have morphine during her crises, because of her responsibilities as a doctor. ‘I wouldn’t be able to function at work,’ she explained, due to the nausea and impaired judgement. ‘I’ll take co-codamol, drink fluids, just get through it.’

Suzanne’s determination to work through physical pain was motivated by her mother’s own self-sacrifice and her defiance against the discrimination she faced at all stages of her career. Her mother, a cleaner and a single parent, had also had the disease and worked ‘sixty hours a week’, recalled Suzanne. Watching her mother work made her see her pain as something normal, and no reason to stop working. This combined with her acute awareness of the prejudice against black people in Britain as motivation to excel academically, because ‘if you’re a black immigrant, you can’t start at the bottom – you have to start at the top’. She was conscious of the sacrifice she felt her mother had made for her and her sister, and the foundations she had laid for their future. ‘We were the second generation. My mum worked so we could have that opportunity. It could not be wasted’.

Suzanne said ‘[w]e got through it, we were like the people from world war times, they learned to make do and mend and get through it. And that’s what we did.’

Situating herself on the inside of the Welfare State, as a doctor giving her

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115 Suzanne (pseudonym), interview with GR, 16 April 2018.
care, and a worker paying her dues, rather than as a patient receiving its benefits, it is striking that Suzanne draws upon a founding myth of post-war British national identity, of ‘Blitz spirit’ and ‘make do and mend’. As Camilla Schofield has argued, national memories of the Blitz and the ‘greatest sacrifice’ were used by Enoch Powell and others to reify Britain and its welfare state as the inheritance solely of its white inhabitants, and to challenge the entitlement and citizenship of its non-white subjects.\textsuperscript{116} Suzanne and her mother’s personal war was that of working as black women, contending with exclusionary institutional racism that demanded nothing but perfection and self-reliance from them, whilst living with a painful illness. Her use of ‘make do and mend’ in this context subverts it, for the ‘Blitz’ myth in part generated the conditions of Suzanne’s own ‘Blitz’. It also speaks to her identity as a British citizen: Suzanne’s sense of belonging and her understanding of British citizenship is wrapped in her sense of herself as overcoming her illness to work, and to prove herself to be a self-sacrificing doctor for, rather than a patient of, the NHS – a worker, rather than a claimant. This capaciousness of World War Two memory and national identity reflects the investment of West Indians at the time – Kennetta Hammond Perry has shown that of the many Caribbean men and women who served in the war, some who did so ‘adopted a sense of Britishness that was both patriotic and capable of serving autonomous desires for social and economic mobility’.\textsuperscript{117} Suzanne’s identity as primarily a doctor rather than a patient is felt in her distancing of herself from patient support groups when they were offered to her by consultants. ‘I thought, well how is that going to help me, swapping cake recipes and knitting patterns,’ she said. She felt that she would be a ‘fraud’ in a patient group as a doctor, and was pessimistic about being ‘welcomed’ by laypeople who ‘describe their symptoms in really odd ways’ and repeat the ‘myths’ common to SCD circles.\textsuperscript{118}

There are many narratives that have not been covered or included in this chapter. It is not an exhaustive or representative summary of the relationship between the NHS and people and families living with SCD. It has sought to show the contingency of these relationships and of individual selfhood upon family and career.

\textsuperscript{116} Schofield, \textit{Enoch Powell and the Making of Postcolonial Britain}, 15.  
\textsuperscript{117} Perry, \textit{London is the Place for Me}, 47.  
\textsuperscript{118} Suzanne (pseudonym), interview with GR, 16 April 2018.
For Denise’s family and Helen, their experience of physical and emotional care as children from the NHS made them feel validated and worthy. In Helen’s instance, this sense of value as a patient and her resultant optimism about the empathy of healthcare professionals coalesces in her memories of asserting herself to unsympathetic nurses. That neither Helen nor Denise reflected in the interview on the possible influence of racism on their experiences may reflect a deep certainty in the citizenship of black people and their entitlement to healthcare. In Suzanne’s case, her experience both as a doctor and a patient in the NHS means that she defines herself as an active agent who vigorously defends her own autonomy, but also believes her value must be continually reconstituted through her work ethic. This speaks to the embodied experience of citizenship – of feeling comfortable and welcome, or not, in the spaces of the NHS; of relating to one’s pain as something that needs and deserves easing, or something that must be pushed through. Herma’s experiences, now particularly impossible to fully recapture, speak to her sense also that she needed to help herself and shore up her resilience with faith. Their assessment of the medical care they or their relatives had received was mixed. The nature of the ‘love-hate’ relationship Anionwu described meant that that was balanced even within individual patients themselves – in the case of Denise and Helen, they felt deep affection for some of the doctors and nurses they had known, though Helen had also known terrible treatment she had an internal standard of how she should be treated and considered those doctors and nurses who fell below that standard to be unprofessional. For Suzanne, her own medical training meant that she felt pragmatic and realistic about the limitations of the NHS, though the discrimination she had received as a black woman and as a person with a chronic illness from her bosses and colleagues gave her few illusions about medical personnel.

Conclusion

For Donald Rodney, the body was a site of creative experience from which observations about the state and assertions of citizenship could be made, and also
could be the canvas upon which these were mapped. As ‘the black body’ had been the subject of such scrutiny by the state, anthropology and medicine, Rodney made his own (in the words of Stuart Hall) into a ‘site of excavation’, to reveal the racist assumptions at the heart of state violence, to untangle the cultural symbolism of blackness, and to meditate upon his own subjectivity. Through this work Rodney illustrated the hospital and the welfare state as a site of state violence and racism, and confronted the stigma of illness and disability in the art world and the black community.

Beyond Rodney’s work, how families affected by SCD went beyond an understanding of the illness as symbolic of present state neglect and violence, and memories of slavery and colonialism, and had implications for intimate family histories. In these instances, cultural understandings of health, illness and relatedness were brought to bear in meaning-making around sickle cell, and the experience of migration was associated with a transformed (or not) understanding of their embodied experience. Some found their familiar embodied experience reframed and medicalized, and others refused their diagnosis or prescriptions and trusted their sense of themselves as healthy. Others, undiagnosed, not informed of their diagnosis or too ashamed to disclose it, died in the UK in the 60s and 70s and their experiences were ‘revealed’ and understood by their relatives and NHS records decades later. Lindee’s concept of a ‘moment of truth’ illustrates how genomic medicine is a collaboration between medical personnel with technical knowledge, and patients and families with lived knowledge. The example of sickle cell disease shows how in the UK this collaboration has at times been a success – as with the work of nurses such as Lola Oni and Elizabeth Anionwu – and at times a failure, as patients’ attempts to articulate their pain and need were ignored by NHS staff.

This collaborative effort is reflected not just in the incorporation of embodied experience and medical information into personal understanding of SCD, but in the relationships SCD patients and families formed with the personnel of the NHS. SCD patients were not just objects of medical attention, they formed, at times, close relationships with the doctors and nurses who treated them. In their claims to their rights to citizenship, they in turn affected the personnel of the welfare state. The oral histories illustrate the ways in which some patients and families felt their
relationships with their treating physicians and nurses to be those of ‘best friends’ and ‘second godparents’ or parents, and according to at least one doctor, these feelings of emotional responsibility were reciprocated. As Perry argues, ‘Black Britons were not merely objects of a race politics governed by the actions and agendas of British officials or a postwar welfare state’. In turn some of these patients and families, as Carolyn Steedman also did thirty years previously, felt their experiences validated and that their personhood mattered. Others, like Suzanne, felt that patienthood was not enough to guarantee her validation and emphasised gaining citizenship through her work as a doctor – understandable given that her career in the NHS had been undermined by racism, sexism and her white colleagues’ judgements about her illness.

In the post-war period, men and women from the Commonwealth invoked their British citizenship and contested deeply-held notions about what it meant to be British through the act of migration. This chapter has illustrated the ways in which the specific rights of British citizens were claimed through entering the spaces of the NHS, through work or treatment. It has also explored their inner lives and how family, politics, art and identity were implicated in this claiming of citizenship. This analysis points to an emotional transition within the claiming of citizenship. In their book *Windrush: The Irresistible Rise of Multi-Racial Britain*, a collection of oral histories from the ‘Windrush generation’, Mike and Trevor Phillips reflected on what they saw as emotional transitions of first- and second-generation migrants. ‘[D]uring the worst of times in Britain,’ they wrote, ‘the regions from which we had travelled became transformed in our minds into idylls, lost paradises within which, in our memories, we still lived, and which, one day, we might physically reclaim.’ But their notion of home – ‘a small fishing village by the Atlantic shore’ – began to feel more distant, and less assuredly the place where they would feel most ‘secure and comfortable’ – instead, their new home became their ‘place’. This new sense of distance from their homelands was partly tied to a ‘mood of assurance’, the Phillips brothers wrote, and

this mood stems from something more than our right to enter the United Kingdom or our familiarity with people and places. During the second half of

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119 Perry, *London is the Place for Me*, 247.
the century another gradual change has taken place in Britain which has fundamentally altered the nature of our relationship with it... If we were engaged in a struggle, it wasn't about our 'acceptance' as individuals. Instead, it was about our status as citizens, and it seemed obvious that if our citizenship was to mean more than the paper on which it was written, it would be necessary for the whole country to reassess not only its own identity, and its history, but also what it meant to be British.120

While racism is still very much a part of British life, the Phillips brothers saw this 'gradual change' as the way in which black communities had brought about a reassessment of 'Britishness'. They sought to make themselves comfortable in the central institutions of the state, though this was a constant negotiation. As Hall put it, in a way that encapsulates the limitations of any chapter dealing with 'black experience', 'there is no 'the black experience' any longer. There are black experiences, there are a rich variety of ways in which blacks are now deeply a part of British life'.121

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Conclusion

This dissertation has made three main claims. Firstly, that the welfare state operated as part of the broader British state in implicitly denying the citizenship of Black British people. Neglect of SCD was implicitly justified by a widely-held belief that it was not a British disease, but a minority condition, which inhibited action across a fragmented central government, Local Health Authorities, and local councils, and meant that SCD patients were perceived as being afflicted by social problems (such as drug addiction) rather than a medical condition. Secondly, SCD patients, advocates and local healthcare workers contested and reconfigured these ethnocentric notions of British citizenship through their demands for improved services on a policy level, and in the everyday experience of entering hospital wards and requesting care when they or their family members were taken ill. Thirdly, shifting notions of what constituted ‘race’, racism and anti-racist action operated from the grassroots to the state level to justify and counter racism. Fears of invoking memories of scientific racism meant the state shied away from making official policy on SCA, even as DHSS tacitly recommended screening on the basis of skin colour, and as Local Authorities invoked stereotypes of cultural racism about African and Caribbean communities and families. From the mid-1970s onwards, SCA activists decried this cultural racism, articulated a critique of institutional racism in the NHS, and invoked notions of biological ‘race’ to generate awareness and support within their communities and to demand government action.

Chapter 1 showed that medical researchers and funding bodies were slow to accept SCA as a condition affecting British residents, focusing instead on the possibilities that SCA apparently held out for advancing understandings of ‘race’ and human difference. Chapter 2 showed that the reluctance of central government to form policy on the issue was the result of a fear that drawing attention to the condition would be ‘eugenic’ and therefore racist, a fear of burdening the health service, and an ethnocentric notion that the condition was not a domestic concern and did not affect British people. The Department of Health distanced itself from the issue, and the Medical Research Council preferred to fund sickle cell research.
overseas. This central inertia meant that the local services, centres and screening programmes that did evolve were often funded through short term grants aimed at the social problems of the inner city, rather than through mainstream health programme funds. Chapter 3 demonstrated that on a local level, SCA was perceived as a social rather than a medical problem: Local Health Authorities responded to the doctors and nurses who lobbied for screening that the condition was not common enough to be cost effective, even in places with the highest African and Caribbean population in the country. On the hospital ward, when people with sickle cell disease (SCD) experienced painful crises, their pain was often challenged and pain relief withheld by doctors and nurses who accused them of being addicts. Chapter 4 showed that, from the mid-1970s, SCD charities worked with nurses and haematologists, raised money to support the development of SCD centres and forged links between healthcare professionals and Black British communities who felt mistrustful of the NHS. Chapter 5 showed that, for first generation migrants with SCD, the process of migration, diagnosis and contact with the NHS reframed their understandings of their bodies, and reordered their memories of their families. Oral testimonies reveal that, for SCD patients, the hospital could be a site of creativity and challenge, where they articulated their entitlement to care and formed emotional bonds with the doctors and nurses who treated them. These testimonies also attest that the experience of SCD, and the long acquaintance with the NHS that it brought, meant that for many it was a form of embodied citizenship, through which their individual identity and relationship with the state was configured and felt.

The first key argument of this dissertation is the operation of institutional racism through, in the words of Beverley Bryan, Stella Dadzie and Suzanne Scafe, the ‘uncaring arm of the British state’.¹ That institutional racism operated within the welfare state, and particularly within the NHS, is important because the NHS has been seen as one of Britain’s unproblematic founding national myths.² This study illustrates in depth the extent to which the NHS embodies and institutionalises the afterlife of empire: shaped by black labour, but often indifferent to the medical needs

of black citizens. Press coverage and popular opinion about the series of events that led to the Windrush scandal which broke in 2018 – including the destruction of the landing cards of arrivals to Britain in the late 1940s – resulted in the resignation of the Home Secretary. Some right-wing newspapers framed it, as the *Daily Mail* did, as ‘a saga of government and civil service incompetence, of ineptitude bordering on cruelty’, or saw it – like the *Telegraph* – as the latest blunder from a Home Office that had been ‘dysfunctional for decades’.

An Ipsos Mori poll found that 61 per cent of the British public agreed that ‘the Windrush scandal is mainly a result of government incompetence’.

These critiques disavowed the role of racism in the exclusion of British citizens from the former colonies. This dissertation contends that bureaucratic incompetence and fragmentation can be deeply informed by racialized notions of citizenship, and that this bureaucratic dysfunction is a tool of the state, effective at evading accountability. This is particularly true of the British welfare state. The state’s failure to collect information about the extent of SCA in Britain was a refusal to ‘see’ it and therefore to take action. DHSS and local authorities employed a range of justifications in order to evade responsibility – the amenability of black families to health intervention; the assumption that, as a ‘black disease’, it could not be a health concern for a British population considered to be mostly white; and fears that action on the condition could be perceived as ‘eugenic’ or racist. These justifications reveal both an ethnocentric state but also one in which different discourses of ‘race’ interacted, and in which ideas of anti-racism could justify racism in the twentieth-century British state.

Institutional racism as a critique and concept has been part of public and political discourse for decades, but its definitions have often been (as Paul Gilroy wrote of the 1998 public inquiry into the murder of Stephen Lawrence) ‘so narrowly and tightly drawn that it excluded almost everybody and left the sources of these persistent but mysterious failures inaccessible to all but the most sophisticated

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management consultants’. This dissertation has sought to unpick these ‘persistent but mysterious failures’ and describe the interlocking set of factors that inhibited the development of SCD services. SCD was not a common disease; in addition, it was a genetic disease in the early years of the development of genetic services in the NHS. Even compared to other genetic illnesses of the time, SCD faced a unique set of problems. These included the state’s peripheralisation of ‘race’ and conviction that the condition was not a British health issue, individual doctors’ and nurses’ racist attitudes towards black patients, and the framing of the condition and its patients as a social problem rather than a pressing medical issue. SCA was also disadvantaged in a health environment where voluntary organisations played a crucial role in the development of services through supplementing the state. Organisations such as SCS dealt with the economic poverty of many of those that they supported – itself a product of wider economic disenfranchisement and unresponsive social services – and did not receive funds from the wealthy supporters that other charities benefited from. Absence of education and awareness – coupled with racist beliefs of individual doctors – led to doctors and nurses misdiagnosing or disregarding the symptoms of SCD, leaving many in unnecessary pain and undoubtedly leading to many preventable deaths. For the black community, long experience with unsympathetic white doctors and racist medical establishments bred mistrust of the NHS and of white doctors, and thus some of the medical interventions that were undertaken – such as the SCD national register and blood donation – could be met with fear and uncertainty. The history of SCA in post-war Britain illustrates the multiple ways in which institutional racism – across different levels of the state and NGOs – operated. Furthermore, this case illustrates that for the health service to ‘decolonize’, issues around poverty and racial discrimination must be tackled, and crucially that people of colour must be meaningfully employed at every level of the NHS and DHSS – not just silo-ed in condition-specific areas.

Having analysed these structures of institutional racism, the final chapter illustrates that these structures did not have a totalizing effect on those who lived within them. Individuals made very different meanings from their experiences. The

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dramatic differences between these citizenships speaks to Stuart Hall’s assertion that “there is no “the black experience” any longer. There are black experiences, there are a rich variety of ways in which blacks are now deeply a part of British life.” Donald Rodney used his body in his work to challenge ideas about ‘race’, masculinity and national identity in a challenge to the ethnocentric British state. For others, like Suzanne, SCD was another way in which her colleagues in the NHS sought to exclude her, and her resilience and commitment to work through the pain was crucial to her sense of herself as a responsible doctor and citizen.

A second argument developed in this dissertation has been that people living with SCD, their families, and organisations such as OSCAR and SCS, contested whitewashed notions of British citizenship through their demand for treatment and their work to implement programmes for diagnosis and care of SCD within the state. Migrants to Britain from Nigeria, Jamaica, Grenada, Ghana and their children claimed the wards and surgeries of the NHS as places where they could heal and be healed. This forms part of what Kennetta Hammond Perry has described as ‘the historical continuum of citizenship practices and imaginaries of belonging that shaped the evolution of race politics and the formation of postcolonial Black Britain’. This contestation could take place at a national level, as with the Merseyside Area Profile Group which submitted evidence to the Home Affairs Select Committee on the poor levels of diagnosis in 1979. On a local level, as Elizabeth Anionwu and Catherine asked their local authorities to undertake SCA screening, and as Lola Oni gave seminars to doctors and nurses about sickle cell pain, health workers made SCA visible and legitimated the pain of those who lived with it. For individuals, as Helen challenged her nurses for being rough with her, and as a desperate mother threatened the doctor who was not putting in an IV for her son, patients and their families invoked their rights to care, and the duty of the nurse and the physician to provide it.

While the NHS has been the site of violence against Black British people, the history of SCA in post-war Britain also demonstrates that the NHS can be adapted

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7 Perry, *London is the Place for Me*, 247.
and changed, and that the present institution has been shaped by the work of the black healthcare professionals who have staffed the service since its foundation in 1948. Paul Gilroy, in his introduction to *After Empire*, reflects on the case of Ingrid Nicholls, a black British woman who faced the amputation of her leg and was informed that she would receive a pink prosthetic limb in 2003. Her case caught national attention and was discussed in a way that, for Gilroy, encapsulated the hope and opportunity of the ‘conspicuous gains brought about in [Britain’s] civil society by an unkempt, unruly and unplanned multiculture’. Her situation – being forced to pay £3,000 herself if she wanted a limb that matched her skin – was described in the press as ‘an affront to her dignity’. Gilroy remarks that ‘[h]er story became an oblique comment upon the ways in which racism has been institutionalized in British social life and a cipher for the possibility that the hurt and injury wrought by racism might be acknowledged and reversed… Britain was rightly ashamed but on this occasion did not turn guiltily away from the source of its discomfort’. Instead, he says, British public opinion identified with her plight, embraced her, and defended her right to dignity. In the example of SCD, the possibility of ‘reversing’ the hurt and injury caused by racism is in many cases impossible, given the pain and sometimes death it has inflicted. However this dissertation has argued that there were transformative instances in which pockets of black and white healthcare professionals, witnessing a denial of the rights of black patients to proper care and dignity, worked together to honour those rights. Gilroy locates an ‘ordinary multiculture’ in the ‘convivial metropolitan cultures of the country’s young people’. This multiculture could also be found in the spaces of the NHS: in the solidarity in the working partnerships of Elizabeth Anionwu and Milica Brozović, George Marsh and Susan Treasure and many others, and the emotional bonds of friendship and care that patients, nurses and healthcare professionals formed in the wards of England’s hospitals.

The third main argument this dissertation has made is that discourses of ‘race’ operated in the service of both racism and anti-racism. During the 1960s and 1970s, the Abnormal Haemoglobins Unit used sickle cell and other mutations to complicate or deconstruct ideas of biological race and distance the discipline of population
genetics from racial anthropology and eugenics, even as they sought to answer research questions that were rooted in rigid notions of human difference, using methodologies that reified racial ‘types’. Between the late 1960s and 1970s, the state at a central and local level was anxious to avoid actions or statements rooted in scientific notions of ‘race’, even as they quietly endorsed a tacit, unofficial policy of screening people on the basis of skin colour. This aversion to discussing biological difference was countered by widely-held cultural notions of ‘race’ and ethnicity, particularly focused on black family structure, education and youth culture. Beginning in the 1980s, at the local level, when faced with patients with SCD, some nurses, haematologists and voluntary groups rejected the tropes of cultural racism that were slowing action and damaging patient care, and used notions of biological ‘race’ as a tool of anti-racism. By leaning into a conception of SCD as a disease affecting black people, thought of by medicine and the state as a ‘black disease’, SCA advocates could show that the indifference of the state was deeply racialized. This approach could be a double-edged sword – SCD organisations could rally their communities to action with a collective sense of identity, but some were alarmed by the focus on the black community in respect to SCD, seeing parallels with the scientific racist strategies of the past and present, and felt stigmatized by it.

State actors utilised discourses of anti-racism to justify inaction on SCA in the post-war period, as public discussions of ‘race’ were too toxic for the central state to handle. The discussions and debates around SCA in the post-war welfare state illustrate what Bulpitt described as the ‘peripheralisation of race’ and what Alana Lentin has called the state’s methods for ‘post-racism racism management’ of deflection, distancing and denial.10 The language of patient-consumer rights could be incorporated into an anti-racist project, reflecting the consumer movement’s origins as a progressive, left-wing movement as well as its co-option by the Conservatives into a justification for the introduction of the internal health marketplace. Duncan Wilson has outlined ‘how a leftist critique of professions, stressing the need for client empowerment, mapped onto a neo-liberal desire to reform professions and public

services on consumerist lines’. In several of the collected oral histories that I draw on in this dissertation, patients and healthcare professionals tied improved services to choice and complaint, and the freedom to go to a different hospital if necessary.

Due to constraints of space and time period, this dissertation could not include the testimonies of many of the younger patients that I interviewed, but their experiences hint at the present state of some services in Britain. Lewis, a 27-year-old man, a junior doctor, showed me a letter that he wrote to a hospital in the Midlands after he was admitted there with a sickle cell crisis in 2012. He reported multiple instances of doctors and nurses reluctant or refusing to prescribe the pain medication that he needed, and the constant suspicion that he was a drug addict pervaded his every interaction with the staff. In his letter, he wrote that ‘[w]hen the experience of pain reaches the point where they feel compelled to seek hospital treatment it is the beginning of a long and harrowing journey through the pain towards recovery. My experiences will illustrate parts of the journey and help you understand the needlessness of this ordeal.’ The parallels between Lewis’s experience and the experiences reported in the primary sources of the 1970s and 1980s make it clear that the stereotyping of SCD patients as ‘addicts’ is not a thing of the past. Another interviewee, Annabel, told of how – following an experience of harrowing medical malpractice in which she received a transfusion of the wrong blood type, barring her from a bone marrow transplant in the future – the hospital sent a psychological counsellor to her bedside. She interpreted this as the hospital’s anxiety that she would sue them, and told her counsellor that she did not intend to make a claim, so he could save his efforts. The counsellor told her that he was there to care for her mental health, and whether she sued or not was irrelevant to him: reflecting an increasing recognition within the NHS (first raised by the SCA advocacy groups of the 1980s) of the emotional as well as physical toll of SCD.

Lewis and Annabel’s experiences raise two points. Firstly, they show that this is not a narrative of straightforward progress and improvement in the treatment of SCD in the NHS. There are developments to point to – the creation of the All-Party

12 Private communication with Lewis.
Parliamentary Group on Sickle Cell and Thalassaemia in 2008, chaired by Diane Abbott MP; the 2008 publication of clinical standards for adult sickle cell care; and the 2012 National Institute for Health and Care Excellence (NICE) quality standard requiring all persons presenting to A&E with a sickle cell crisis to receive pain assessment and appropriate analgesia within 30 minutes. Nevertheless, the quality of treatment varies dramatically across the country, due in part to the legacy of the patchwork service that emerged in the 1970s and 1980s. Healthcare professionals’ attitudes towards SCD sufferers, and particularly their pain, continue to be negative, illustrated by the case of Sarah Mulenga, who died in 2011 following a sickle cell crisis when two paramedics refused to take her to hospital. Secondly, these experiences record a shift in terms of the methods of redress available to people living with SCD since the 1980s. These younger SCD patients have a sense of themselves as consumers of a service, who can choose whether to hold the health service to account, and know that legal action is possible. From the 1990s onwards a succession of public bodies entrusted with regulating the health service were created, such as the Commission for Health Improvement (created 1999). Today, the Care Quality Commission (2009), NHS Improvement (2016) and the Parliamentary and Health Service Ombudsman (2017) are the present incarnations of organisations conceived to provide institutional legitimacy to patient complaints, though there is disagreement about the extent to which patient complaints are heeded in reality.

Writing in 1985, Bryan, Dadzie and Scafe detailed the history of the relationship between black women and the NHS. They argued that

[w]hen Black women began arriving in Britain after the Second World War to provide the newly-established National Health Service with much-needed labour, we came into a service which regarded us not as potential clients but as workers… Since we were never identified as potential consumers of the service, our health needs did not enter the debate about the kind of health provision the country would establish.\textsuperscript{16}

This dissertation has shown how this dynamic of indifference and exclusion played out across the institutions of the post-war welfare state. That dynamic was countered both by the Black British workers who built the NHS, and by the Black British consumers who used the service and demanded care. What Bryan, Dadzie and Scafe described as ‘individual and collective acts of defiance and resistance’ took place within the walls of the welfare state, as Black Britons entered the debate around health provision as both workers and consumers, and demanded the rights to heal and be healed. This litigation over sickle cell sought to rectify the gap between the entitlements of Black Britons to healthcare in principle, and the reality of a service unwilling to guarantee those rights. By making sickle cell a visible health issue in the language of public health, and compelling the state to see the people it was charged to care for, these patients, nurses, doctors and volunteers invoked the citizenship of Black British people, and presented an alternative vision of the welfare state.

\textsuperscript{16} Bryan et al, \textit{The Heart of the Race}, 89.
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