Research Reflective Report

Investigating the effect of categorical thinking on misconceptions and stigma towards sickle cell patients in the UK healthcare system.

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Contents Page

Abstract

Sickle cell disease (SCD) is often managed through discrete genotype categories (HbSS, HbSC, and HbS-beta thalassaemia). These categories are treated as reliable determinants of disease severity and resource allocation. This report explores the degree of influence categorical assumptions and diagnostic essentialism influence the NHS' approach to treating SCD, despite evidence disputing genotype as an infallible measure of disease severity. Through analysis of NHS policy, clinical and sociological literature, this report argues that genotype-based classification fulfils administrative work rather than clinical ones. It is this, as well as the racialised history of SCD and black individuals in healthcare that produce medical stereotyping and stigma. A major disconnect between formal NHS guidance that encourages individualised, presentation-based assessment (NICE CG143) and documented clinical practise has also been identified in this report and is evidenced by NHS commissioned studies as well as coronial findings of Evan Nathan Smith and David Onawelo. This categorical logic is even present in the allocation of treatment of Hydroxyurea. This report concludes that categorical thinking in SCD care, stems from failures in the implementation of existing guidance, rather than flaws in the guidance itself. Recommendations that focus on guidance review, consistent care plan usage and improved mandatory training are proposed to help reduce the effects of categorical thinking witnessed in clinical practise.

Section 1: Introduction

Background

Sickle cell disease (SCD) is a group of inherited red blood cell disorders caused by a mutation in the gene responsible for producing beta haemoglobin, the protein that carries oxygen in red blood cells (Elendu, et al., 2022). This mutation results in the formation of abnormal haemoglobin (HbS), which become rigid, and sickled in shape upon exposure to low oxygen and can lead to various health complications such as vaso-occlusion, chronic anaemia and acute painful episodes known as vaso-occlusive crisis (Elendu, et al., 2022).

Over 19,00 people are estimated to be living with sickle cell disease in the UK(The sickle Cell Society and All-Party Parliamentary Group on Sickle Cell and Thalassaemia, 2021), making it the most common inherited blood disorder in the country (Dormandy, James, Inusa, & Rees, 2017). SCD disproportionately affects individuals of Black Arican and Caribbean descent (Office for Health Improvement and Disparities, 2014). However, it does also occur in populations with historical exposure to malaria such as those with Mediterranean, Middle Eastern, and South Asian heritage (Elendu, et al., 2022). Unlike what is commonly believed, Sickle cell is not a disease with repeating symptoms throughout. Individuals with the disease show differing amounts of variable expressivity, this includes pain frequency, organ damage and disease severity even among patients with the same genotype (Rees, Bain, & Littlewood, 2021).

Despite this, a large proportion of SCD management fails to take it into account this variety (Rees, Bain, & Littlewood, 2021). NICE guidelines regarding the management of acute painful sickle cell episodes (CG143), advises clinicians to approach with individualised, symptom-based management with referral to the individuals care plan rather than genotype-based sorting (National Institute for Health and Care Excellence, 2012). However, in practise SCD treatment is often sorted via genotypic categories such as HbSS, HbSC and HbS-beta thalassemia (Dyson, 2019), which are then used as a reliable and foolproof indication of disease severity and a tool when dictating resource allocation (Dyson, 2019).

This gap between practise and guideline is evidenced by The Sickle Cell Society and APPG's No one's listening (2021) report. Within the inquiry, it was found that despite a generally high standard of care within specialist haemoglobinopathy services, considerable amounts of care failings on general A&E departments and in wards have led to patient deaths and frequent 'near misses' (Sickle Cell Society and All-Party Palimentary Group on Sickle Cell and Thalassaemia , 2021). These finding and others such as a lack of knowledge regarding SCD among healthcare professionals, with patients and their families often having to educate staff about the disease, while experiencing significant amounts of pain as well as repetitive lack of compliance towards national standards on pain relief in A&E (Sickle Cell Society and All-Party Palimentary Group on Sickle Cell and Thalassaemia , 2021). These experiences contrast the CG143 guidelines that advise against categorical shortcuts and instead promote individualised assessment and quick pain relief (National Institute for Health and Care Excellence, 2012).

The ideology of genotypic categories doing administrative rather than clinical work was described in Dysons 2019 book. These categories help make complex biological and social ideas

more manageable and allow for quick decision making by institutions (Neil & Bodenhausen, 2000). Consequently, this can make space for incuriosity and a disregard towards the patient's actual clinical needs by healthcare professionals (Dyson, 2019). This human way of thinking categorically, or it's more healthcare specific counterpart, diagnostic essentialism, treats genetic categories as though they are fixed and predictive with 'inherent discoverable essences' (Rohlfsen & Parsons, 2025).

In SCD, categorical thinking intersects with decades of medical racism in the form of Cartwrights writings describing black people as being "insensible to pain when being subjected to punishment" and his creation of pseudo-scientific terms such as "drapetomania" and "dysaesthesia aethiopica", to pathologize black resistance to slavery (Guillory, 1968). As well as Thomas Hamilton's assertations that black people experience "less pain" after conducting extremely painful experiments on John Brown, an enslaved man in the 1980s (Villarosa, 2019). These misconceptions have only continued into modern day medicine with documented racial bias in the assessment and treatment of pain (Hof16) and in a 2016 study where over half of 222 white medical students endorsed at least one myth about physiological differences between black people and white people (Hoffman et al., 2016)

Individuals with SCD can be understood as holding what Goffman (2009) would describe as a stigmatised identity with racialised assumptions about pain tolerance and drug-seeking behaviour resulting in patients not just being miscategorised, but also discredited (Hoffman et al., 2016)

The institutional source of analysis within this report is the National Healthcare System (NHS). Being a nationally coordinated system with well-documented policies and guidance such as NICE CG143, allows for the identification of different categories used in the treatment of SCD. In addition, the No One Listening report as well as its 2025 follow up from the NHS race and Health Observatory, showcase the NHS recognising failings in SCD care and management (Sickle Cell Society and All-Party Palimentary Group on Sickle Cell and Thalassaemia , 2021), (NHS Race & Health Observatory, 2025). Finally, understanding how categorical thinking works within the NHS aligns with my intended future career in genetic counselling.

Aims & Objectives

This report aims to examine how Categorical thinking and Diagnostic essentialism shape the treatment of SCD patients within the NHS. Focusing on the gaps between the advised individualistic approach towards treatment and the categorical, genotype-based approach observed within hospitals as well as its effects on the stigma and misconceptions surrounding SCD in employment

Objectives are to:

- Establish what categorical thinking is as a mechanism of harm, and the effects of racial bias on categorical thinking in clinical settings
- To explore whether genotype-based assumptions can conflict with individualised, symptom-based care.

- Examine the differences between formal NHS guidelines and patient's actual experiences of care and why they occur
- Use these findings to create recommendations

Section 2: Methodology

Approach

Rather than looking to create new primary data, this report employs a thematic narrative synthesis framework to evaluate the role of categorical thinking in the stigma and misconceptions against individuals with Sickle Cell Disease within UK healthcare.

Research design

An interpretivist approach is used to critically synthesise literature across biomedical sciences, genetics, the history and philosophy of science, and studies of race in medicine. Literature on biomedical sciences provide the clinical background to this report in which the historical and sociological literature can then link with. Biomedical findings (e.g. clinical unreliability of genotype as a severity predictor), were synthesised with a philosophy-of-science critique of categorical/essentialist thinking and then linked with a race-and-medicine account of how such categories can become racialised in practise. These combined sources were then evidenced by patient-experience/inquiry reports (No One's Listening, 2021; NHS Race and Health Observatory, 2025) and NHS policy documents (NICE CG143, BSH guidance) to provide a practical NHS specific link.

Instead of broadly surveying all disciplinary areas mentioned above, this report specifically focuses on the mechanisms connecting genotype-based categorisation, diagnostic essentialism, and their documented consequences within NHS SCD care. This was used to determine what literature was used.

Sampling

This report did not collect new data; therefore 'sampling' here relates to the method in which reviewed literature was selected. Sources were using targeted keyword searches, rather than a formal structured, comprehensive search strategy. Key terms used included, categorical thinking, sickle cell disease, stigma, disease severity, diagnostic and genetic essentialism, medical stereotyping and bias. These terms were searched across PubMed, HIH, Google Scholar, NICE's guidance database, and the University of Leeds library catalogue.

Sources were filtered by their relevance to themes, UK applicability and academic or institutional credibility (e.g. Peer-reviewed journals, recognised national bodies and charities such as NICE, The Sickle Cell Society, and the NHS Race and Health Observatory). In the case of UK-specific evidence unavailability, international literature was used contextually rather than to infer direct NHS practise. For instance, because no UK studies on clinicians racialised beliefs surrounding SCD patients were found, a US study (Hoffman et al. 2016) was used. This geographic limitation was made clear.

Ethical considerations

This report does not use any primary data, neither has any primary research with human participants been conducted. However, patient and other forms of individual testimony from secondary sources such as the No One's Listening report, are used only to evidence patterns and themes. This is to avoid repeating at times, painful testimony without any analysis. In

addition to this, given that SCD predominately affects black patients in the UK and the central argument in this report being racialised bias in clinical settings. I as a member of the Black-British community, have had to examine how my own identity, beliefs, and background influence the information I have analysed and share throughout. I aim to represent all literature accurately, rather than with selectivity. Finally, no private patient records were accessed or used in this report, all sources are publicly available.

Section 3: Literature review

The limits of Genotype as a predictor of disease severity

A growing body of literature has demonstrated that genotype alone, is a subpar predictor of disease severity in SCD (Dyson, 2019; Rees et al., 2022; Rohlfsen and Parsons, 2025). Rees et al. (2022) demonstrates that patients with matching genotypes can experience very different symptoms and attributes severity as multifactorial, rather than a set consequence of genotype alone. These factors include modifier genes, access to care, environmental exposure and chance(Rees et al., 2022). Bain et al. (2025) even argues that due to the sheer variability observed within SCD, scientific journals and presentations, should endeavour to specify what sense of "sickle cell disease" is being described because of the wide number of clinical presentations and outcomes across each genotype.

Factors contributing to this variable expressivity include genetic modifiers (Rees et al., 2022). Foetal Haemoglobin (HbF) production usually stops after birth (Akinsheye et al., 2011). However, some patients with SCD have unusually high levels of HbF, specifically those with the Senegal and Saudi-Indian haplotype who show high HbF retention into adulthood (Akinsheye et al., 2011). Unlike adult haemoglobin (Hb), Foetal haemoglobin' structure disallows it from being affected by the sickle mutation and high levels have been attributed to a reduction in intracellular HbS concentrations (Rees et al., 2022). Providing an important anti-sickling effect and reducing disease severity and symptoms (Rees et al., 2022).

Adding to this, co-inheritance of alpha-thalassaemia in HbS-beta thalassaemia can modify the phenotype of HbSS positively by decreasing the rate of haemolysis and stroke (Quinn, 2016) but also negatively with some evidence demonstrating an increased rate of painful episodes with high alpha-thalassaemia levels (Quinn, 2016). Neither of these modifiers are factored in by classic genotype classifications alone, this makes it so that two patients with the same primary diagnosis, may have vastly different clinical trajectories.

Environment and socioeconomic factors such as climate, air quality, access to exercise, infection exposure and socioeconomic status also contribute to disease severity (Rees et al., 2022) Mortality rates between low-income regions, such as most of sub-Saharan Africa and high-income regions such as the USA and Europe vary drastically (GBD 2021 Sickle Cell Disease Collaborators, 2023). Sub-Saharan Africa accounts for over 70% of global sickle cell deaths with childhood mortality rates as high as 80%, while the U.S. and Europe, experience less than 2% of deaths with childhood mortality under 1% (GBD 2021 Sickle Cell Disease Collaborators, 2023). This gap can be explained by the available healthcare options (newborn screenings, hydroxyurea etc) and finances rather than any difference in genetics (GBD 2021 Sickle Cell Disease Collaborators, 2023).

Another, more debated environmental factor for SCD is the weather. A vast majority of individuals with SCD attribute cold weather as a trigger of acute pain (Rees et al., 2022). Despite inconsistent evidence linking the two, patients are commonly advised to stay warm (Rees et al., 2022). One UK study found an association between humidity and fewer hospital admissions as well as a "weekend effect" with lower admission rates in London over the

weekend (Piel et al., 2017). Rather than indicating physiological effect, this data reflects more on patient behaviour, specifically the refusal to seek care during bad weather. This goes to show that even environmental factors can be impacted by behavioural and social factors.

When looking at the totality of evidence, the assumption of genotype categories such as HbSS and HbSC in clinical practise as the sole indication of disease severity falls short. The NHS own patient guidelines on SCD even mentions that sickle cell disease varies between individuals from mild to serious, but most people with it lead happy and normal lives (NHS, 2022), acknowledging the variety of clinical presentations within the condition. If phenotype does not straightforwardly follow genotype, how can genotype-based treatment and resource allocation avoid mismatching a patient's actual needs?

Categorical thinking doing administrative work

Dyson (2019) critiques the idea of genetic reductionism, arguing that diagnostic categories often function as administrative tools. The clinical classification of SCD genotypes by severity, where protocol treats HbSS as most severe, while HbSC and HbS-beta thalassaemia are inherently milder, ignores within genotype variation and parallels Dyson's critique, allowing for institutions to triage and allocate resources efficiently rather than engaging with the complex genetic and socio-economic factors affecting each individual patient.

This is genetic essentialism made clinically visible, Nelkin and Lindee (1995) describe genetic essentialism as the reduction of the individual, with all their social and biological complexities, to their genetic code. At the clinical level, diagnostic essentialism operates similarly overlooking the lived reality of the condition, and treating each patient as possessing a fixed, discoverable "essence" corresponding to their diagnosis (Rohlfsen and Parsons, 2025)This results in healthcare workers placing expectations on a patient based on their category rather than their actual presentation.

Hydroxyurea, a treatment used to alleviate symptoms of SCD, has typically been reserved for those with a more severe disease phenotype in UK paediatrics (Phillips et al., 2018). The British Society for Haematology (BSH) criteria regarding hydroxyurea allocation in SCD (Qureshi et al., 2018), as well as other international sources (Cheng et al., 2026), are based upon Sickle cell anaemia (HbSS). This is despite a growing body of evidence detailing other genotypes (HbSC and HbS-beta-plus thalassaemia) being able to clinically benefit from hydroxyurea (Phillips et al., 2018).

Present data has shown that despite HbSC being historically attributed as a milder form of SCD, patients with this genotype can experience severe outcomes typically attributed to HbSS (Cheng et al., 2026). However, they are continually underrepresented in both hydroxyurea research and prescribing guidance that focus on HbSS as the default (Phillips et al., 2018). This produces an environment whereby drugs known to alleviate symptoms, are allocated through genotype category instead of individual disease severity, especially when the patients genotype lies outside of the category in which the guidance was based on.

As stated previously, this categorisation allows systems such as the NHS to allocate resources, funding, specialist knowledge, training and even drug allocation efficiently and at a large scale (Dyson, 2019). However, this efficiency can come at a detriment to the individual patient, and this is observable in the NHS Race and Health Observatory's (2025) review. The review found that in the UK, SCD has only two approved treatments including a gene therapy called Casgevy and Hydroxyurea, with the former limited to approximately 50 patients a year (NHS Race and Health Observatory, 2025). This in vast contrast with Cystic fibrosis which has seen multiple treatment advancements in recent years (NHS Race and Health Observatory, 2025). This increases the risk of professional failure in recognising when patient symptoms lie outside of the expected genotype assumptions, and consequently, the availability of treatment options that could alleviate symptoms.

Stigma in SCD

Goffman's (1963) concept of stigma allows for an understanding of how diagnostic essentialism displays itself during individual clinical encounters. Once the individuals condition becomes the primary way in which they are viewed, other parts of their credibility are now called into question, and their self-reported pain is undermined. This is evidenced by Hoffman et al. (2016), who found repeated racial bias in the assessment of black pain, and false beliefs held by white clinicians surrounding pain tolerance between white and black patients, though these findings are constrained by a US-centric sample.

It is also evidenced in the No One's listening report, where many testimonies spoke about a general disbelief by clinicians and nurses with one individual reporting hearing comments from hospital staff such as, "You could at least look a little bit more unwell, you look absolutely fine, what's wrong with you, should you be here?" (Mensah, cited in Sickle Cell Society and All-Party Parliamentary Group on Sickle Cell and Thalassaemia, 2021, p. 40). These categories do not just determine the individual's care; it outweighs what the patient is saying to the clinician.

Dyson (2021) argues that the despite the clinical advances of SCD as it's typical genetic model, it can mask it's social and racial aspects. Similarly to how disease severity is reduced to genotype, a patient's actual lived experiences are bound to their genetic profile, with little space for factors outside those limits. Where symptoms cannot be explained, stigma fills that gap, and assumptions take over. Following a study of SCD in Nigeria, patients described negative reactions from family, friends, co-workers and their wider community, and used Goffman's ideas, identifying their stigma as arising from societal norms instead of from their conditions (Ola et al., 2016). Ola et al. (2016) further argues that many prior studies have failed to take societal context into account, instead clinicians and researchers have frequently individualised the problem as located within the patient.

When meeting together in focus groups, participants in Ola et al. (2016) were able to separate the stigma they experience, from the disease itself and create pushbacks to take on into wider society, indicating that the stigma was never inherent to SCD. This aligns with Dyson's (2019) wider argument that stigma is contingent rather than fixed as it relies on false assumptions

surrounding the disease rather than any real aspects of SCD and can therefore be dismantled by showing that the assumptions behind it, are false.

Taken together, this all suggests that the stigma observed in SCD is not inherent to the disease, but instead a consequence of categorical thinking. Specifically, when the patient is treated wholly by their genotype, and any outliers are explained via assumptions. If their diagnostic labels generate the stigma, then correcting the assumptions built into that label, rather than treating stigma as an unavoidable feature of the illness, could lead to change.

The gap between guideline and practise in NHS policy

NICE's CG143 guidance recommends that:

- Clinicians use an individualised, symptom-based assessment upon presentation of a patient in an acute sickle cell crisis.
- Regard the patient and their families as experts in their own condition and take their opinions into consideration.
- Clinicians should treat an acute painful sickle cell episode as a medical emergency and offer analgesia within 30 minutes of presentation

However, research commissioned by the NHS Race and Health Observatory found that this guidance had not been designed for the high-pressure settings within the NHS such as ambulances and A&E, and evidence was found that the guidance was not even being used or consistently applied in practise (NHS Race and Health Observatory, 2025). The report describes CG143 as reference-style clinical guidance instead of actionable advise that can be used by non-specialist staff during significantly time bound emergency situations (NHS Race and Health Observatory, 2025).

Staff are advised to follow individualised care plans but with high staff turnover, workforce shortages and extreme pressures of A&E departments and ambulances, staff are at times unable to follow them and they are frequently dismissed (NHS Race and Health Observatory, 2025). Adding on to this, inconsistent access to the National Haemoglobinopathy register, a database that records clinical data for patients with inherited red cell disorders (The National Haemoglobinopathy Register, 2017), only ensured a lack of individualised care.

The Sickle Cell Society and APPG's No One's Listening (2021) inquiry only confirms this, with wide-spread non-adherence to national pain relief standards, a lack of SCD awareness among non-specialist healthcare professionals and a lack of communication between different wards. One individual within the report even testified that they had been hospitalised in wards where doctors have asked them, "What do we do for you, I have no idea at all?" (Sickle Cell Society and All-Party Parliamentary Group on Sickle Cell and Thalassaemia, 2021, p. 28) as well as delays and googling by hospital staff during patient emergencies (The sickle Cell Society and All-Party Parliamentary Group on Sickle Cell and Thalassaemia, 2021)

These failings have unfortunately proven fatal with the death of Evan Nathan Smith due to a chain of institutional failures, a lack of communication between wards, failure to recognise his SCD by a nurse and refusal to administer oxygen by staff at North Middlesex Hospital triggering

the AAPG inquiry (BBC News, 2021). Many similar cases have occurred throughout the years with the recent 2023 passing of David Onawelo due to critical failures in recognising acute deterioration and what the coroner described as a lack of compassion and clinical curiosity among medical staff (Irvine, 2024) and a further case of Shen'iyah Green, who was misdiagnosed despite her mother providing repeated warnings of her SCD diagnosis (Slater + Gordon Legal Services, 2025). Information in the patients record or provided by the patient or their family was provided in all three cases, but each was ignored or overlooked by staff using their own assumptions.

Gaps in literature

This report addresses the gap between clinical work on phenotypic variability, the sociological question of why institutional use of categorical thinking remains and policy reports that provide outcomes without their cause. It uses categorical thinking and diagnostic essentialism to connect across clinical, sociological and NHS practise literature.

Section 4: Conclusions and future directions

Conclusions

Table 1: Summary of key mechanisms and evidence

Mechanism	Key evidence	Links with the NHS
Genotype ≠ Severity	Considerable variable expressivity witnessed within genotype subtypes. Severity is instead linked with modifier genes, environment and access to care (Bain et al., 2022; Rees et al., 2022).	This pattern is acknowledged by the NHS in their own patient guidance (NHS, 2022).
Medical stereotyping and Stigma	Racial bias present in the assessment of black pain, and stigma is a product of social context, rather than inherent to the disease (Goffman, 1986; Hoffman et al., 2016; Ola et al., 2016; Dyson, 2019).	No One's listening report includes testimony pertaining to assumptions of drug-seeking behaviour and lying about pain by clinician and nurses(The sickle Cell Society and All-Party Parliamentary Group on Sickle Cell and Thalassaemia, 2021).
Categorical thinking doing administrative work	Genotype categories are used to allocate resources and triage efficiently but can be detrimental to the individual patient and accuracy of diagnosis (Lindee and Nelkin, 2004; Dyson, 2019).	Prescription of Hydroxyurea (Hydroxycarbamide) is genotype gated (Qureshi et al., 2018).
Gap between guideline and practise in NHS policy	Guidelines surrounding SCD do not reflect the true high-pressure emergency use in A&E departments and ambulances. Additionally, these guidelines are not consistently adhered to(NHS Race and Health Observatory, 2025; National institute for Health and Care Excellence (NICE), n.d.).	The passing of Shen'iyah Green, David Onawelo and Evan Nathan Smith.

This report aimed to examine how categorical thinking and diagnostic essentialism affect the treatment of Sickle cell disease (SCD) in the NHS. Specifically, the differences between guideline backed, individualised care with a focus on care plans and the categorical, genotype-based approaches that continue within actual clinical practise. This report has made use of different forms of media to evidence that categorical thinking used in the treatment of SCD, causes more harm to individual patients than it does benefit them.

Evidence used in this report discredits genotype as an infallible predicter of SCD severity, but institutions continue to use genotype as an accurate measure of severity, resource allocation and hydroxyurea treatment allocation to just a few. Dyson (2019) argues that this continuous institutional use of categorical sorting is not accidental. Instead, it allows for the easy management of any complexities, even at the detriment of the individual.

When this categorical ideology meets the decades of racialised history surrounding SCD and black people within healthcare, it shapes itself into medical stereotyping and stigma and has a significant impact on if a patient's pain and other self-reported symptoms are believed. This unfortunately, these issues are not simply theoretical. While guidelines such as NICE's CG143, call for individualised, presentation-based assessment, official NHS inquiries show that they have either been implemented poorly or ignored entirely. Add on the cases of David Onawelo, Shen'iyah Green and Evan Smith Green and we can see that these discrepancies between guideline and practise, have and continue to prove to be fatal.

Table 1 summarises these mechanisms and their supporting evidence. The finding consistent throughout each form of literature is that SCD care is not strictly a failure of guidance, but rather a failure in its implementation.

Strength of evidence and limitations

The reliability of evidence within this review, varies. The weak correlation between genotype and disease severity is highly evidenced by various peer-reviewed clinical literature (Piel et al., 2017; Bain et al., 2022; Rees et al., 2022). Similarly, there is strong evidence to back the claim that this weak correlation leads to genotype-gated treatment access, with British Society for Haematology, hydroxycarbamide prescribing guidelines restricting it's benefits to only children with HbSS and HbS-beta-zero-thalassaemia (Qureshi et al., 2018). Finally, the gap between guideline and actual practise is well evidenced by the NHS' commissioned research which showcase direct admissions of failings (NHS Race and Health Observatory, 2025).

However, claims surrounding the actual process through which categorical thinking produces stigma towards an individual in clinical situations are largely deduced from theoretical works (Goffman, 1986; Dyson, 2019) rather than from empirical evidence.

This report has been written entirely from secondary literature and prior inquiry data rather than primary research. In one respect, this structure has worked well for the timeframe in which it was written, but no new empirical evidence has been provided to support findings.

Future Directions

Future research should focus on collecting primary qualitative data by speaking with clinicians and nurses about their experiences of categorical thinking within SCD and why it continues to persist despite discouragement from official guidance. This will also allow for a more direct comparison between Dyson's (2019) explanation of how categorical thinking present itself in administrations and the accounts of actual clinicians who experience high-pressure decisions daily.

Additionally, there is a lot of international evidence of genotype-dependant prescription of hydroxyurea patterns in comparison to the UK. A review of these patterns across different NHS trusts would strengthen the evidence currently available. Finally, continuous monitoring of adherence to guidelines such as CG143 and implementation of universal care plans, would help ascertain if the gap between guideline and practice is definitively reducing.

Recommendations

Using what has already been discussed, this report proposes these three recommendations.

Table 2: Recommendations

Recommendation	Rationale
Hydroxyurea prescribing guidance should be reviewed to make sure individuals diagnosed with HbSC and HbS-beta thalassaemia are not left out of discussions surrounding the benefits of hydroxyurea based Soley on their genotype	Evidence increasingly shows that these genotypes are not as mild as previously thought. Consequently, current guidance should use the same approach as is used in HbSS.
Promote a consistently uniform use of Universal Care Plans and mandatory triage alerts for all NHS trusts to encourage consistency in the delivery of care.	This recommendation has previously been introduced following the passing of Evan Nathan Smith and David Onawelo. It hopes to address the inconsistent application of CG143
Formally require comprehensive SCD-focused training for nurse and emergency medicine professionals. This would include disease management as well as the racialised misconceptions identified through patient testimonies in the No One's Listening (2021) report	The No One's Listening (2021) report found current training was quite general and not tailored well to SCD, resulting in inadequate knowledge of the disease among healthcare staff

Reflections on my research Journey

Description and feelings

Prior to this project, my research experience was almost entirely quantitative. This included lab reports with clear hypotheses, controlled variables and numerical results. This allowed for easy comparison and provided me with a clear plan on writing up my methodology and lab reports. Upon beginning my research, I had a wide scope of ideas and areas of interest that I wanted to explore in my project, including collecting primary research. In hindsight, I underestimated the amount of work involved and the lengthy ethical approval timeline from the NHS and set myself a scope that was beyond what I could effectively manage. Consequently, I became slightly overwhelmed and had to reconsider the projects scope. This meant pivoting and changing my approach to the project.

Before meeting with my supervisor for the first time, I wrote up summarised notes to ensure I remembered to mention all the important details. This helped significantly as it helped to structure the meeting and meant I left with concrete next steps. The meeting did end up going well, and I was told that I was on the right track. This encouraged me to continue going, and book/literature recommendations from my supervisor helped shape my future research, especially the sociological aspect of genetic conditions.

I was experienced a lack of confidence in my own abilities, particularly because my supervisor was a professor with a wide breadth of knowledge in the field of philosophy and science. I was extremely aware of the gap between their experience and mine and found myself worrying I would not meet their expectations. Looking back now, I recognise this as imposter syndrome and that supervision helped to support my learning rather than judge my abilities.

My feelings and emotions have drifted week by week during this project. The first few weeks were made harder by our Laidlaw trip to Selside, in the Yorkshire Dales. Little service and a packed schedule of hiking, climbing and caving made it impossible to start my research. This was a big jump for the me who was used to university lab structured work. However, upon arriving back home I made better use of the time available to me, created a more structured schedule, and prioritised key tasks helping my project find its shape.

Challenges

A significant challenge I faced during this project was writing up my methodology. As I mentioned earlier, I wanted to incorporate primary research into this project by interviewing patients with SCD or clinicians and asking them their experience of categorical thinking and stigma within the NHS to help support my arguments with patient testimony.

However, after seeking advice from my supervisor, I quickly realised that NHS ethical approval for primary research involving patients could take several months, falling way outside the length of my research. As a result, I had to change my project from a mixed primary/secondary design to a literature-based critical analysis. At the time, this felt like a major obstacle to my progress because I had a clear idea of how primary research would contribute to my project. Looking

back now, this experience was good as it pushed me to deeply engage with literature and research.

My early research kept leading me to further explore SCD and its significance in wider community and cultural contexts outside of clinical settings. Resultingly, I found myself following these threads further than what my projects actual focus needed, to the point where my work began to become unfocused and undirected. Recognising this tangent I was on, was difficult as there was so much more individually interesting work, but irrelevant to my topic. Narrowing this report specifically to SCD in NHS healthcare, meant moving away from work I had already put effort into. I felt as though I had missed out on information but speaking with my supervisor regarding this was reassuring. He informed me that this process was normal and a valuable part of the research process. This helped me change my perspective on the situation from one that felt like information wasting to a specific and calculated methodological decision that has helped me improve my research. Going into the future, I will use this perspective in my research, that narrowing down my research, helps it become specific and allows me to answer questions better.

An unexpected challenge I faced was changing the way I had to think. My Biomedical Science degree has included lab reports, built a strict hypothesis, controlled variables and mostly quantitative results, allowing for a written report that follows the collected data. This project has required me to synthesise various forms of literature including sociological, theoretical and policy literature into a single argument. This thematic style of approach was a hard adjustment as I had to trust concepts like categorical thinking and diagnostic essentialism to build a trusted argument. I too some time to get used to this.

My time management during the first few weeks of the project was a real weakness. I found it harder to manage my time effectively making it harder to make progress and structure my project. If I were to undertake this kind of projects again, which I likely will at university, I would set mini deadlines for myself with a specific time and date prior to beginning my research period. I would treat each stage as if they were individual university assignment with strict deadline, this would allow me to track my progress. I would also schedule regular breaks between research sessions rather than pushing through 7–8-day stretch, as I found that I would burnout, reducing my productivity during these sessions.

Evaluations

Reflecting on the first few weeks of my project versus the end, shows the growth I have experienced:

In the first few weeks, I could not follow my plan and resultingly focused on:

- Responding to feedback,
- Adjusted scope following the ethical approval issue

There was limited communication between my supervisor and I dues to my previously mentioned lack of confidence and uncertainty about the best time to ask for help. I instead worked through issues myself, without requesting the needed help.

Towards the last few weeks of my project, this began to change:

- I had a clearer direction of research
- Developed confidence and began to proactively book meetings with my supervisor to monitor progress
- Asked for help if a section looked wrong or for general guidance
- Implemented a proper plan with deadlines

This change in how I worked was extremely beneficial, as it helped overcome a pattern I have noticed in myself, a tendency to struggle independently and stay silent rather than seeking support. For example, figuring out if a certain piece of literature fit into the context of my project. I spent a long time trying to fit in a case study regarding the treatment of SCD in prison healthcare before a quick talk with my supervisor helped me solve it. Recognising this pattern of mine and actively working on it by booking meetings and listing things to mention prior beforehand, will help me in the future, especially in my upcoming role as faculty representative.

After valuating my time management during the first few weeks of this project, I can honestly say it did not go as well as I planned it to. I had previously planned to focus on different types of literature each week, however the trip to Selside and ethical approval issue, my progress in weeks one and two were slower than they should have been. Towards the last few weeks of research, I developed a consistent routing which included 4 days in the library and three days to decompress and think. This helped improve my productivity and standard of work as I had a clearer understanding of the projects direction and structure and could now focus on analysis of my chosen sources.

Although the beginning of this project was hard, with ethical approvals, changing methodologies and issues with time management, I developed confidence and habits that allowed me to improve my approach to research and will help me in my future endeavours.

Leadership Development and Growth

The Laidlaw programmes three different leadership capacities include People, Performance and Process. During the process of my project, I have experienced all three.

1. <u>People</u>

   My communication, and emotional intelligence have developed the most through this project. My nervousness to work with my supervisor arose due to my awareness of the gap of experience between us both as an undergraduate student and a professor. I felt some sense of imposter syndrome and that I wouldn't be able to meet expectations due to my limited experience in academia. To help manage the anxiety and nervousness I was experiencing, I wrote up notes prior to our initial meeting as I could rely on it rather than feeling pressure to respond while nervous.

   I have had to build a more collaborative mindset and realise that asking for help, doesn't make you weak or mean failure. Instead, it is an expected part of the process in research and everyday life.

2. Performance

The shift between writing lab reports to synthesising theory across different disciplinaries and sources has required a lot of reflection and critical thinking. Lab reports require you to critically assess your data and check your methods for their validity. In this report critical thinking has looked more like, looking at theoretical arguments for categorical thinking within Sickle cell disease and finding actual clinical literature on the links between genotype and severity. This habit of comparing the claims of two different sources with one another has developed through this project.

My initial strategy to complete my period of research was completely reshaped after the issues with the NHS ethics approval and our Selside trip. My vision of what the projects results would be, changed with it. I actively re-strategised, adapting my aims to a literature-based review rather than primary research. I found a gap within the available literature, and I aimed to address it.

Another benefit of this process has been my exposure to researchers I wouldn't have known about without it. Through conversing with my supervisor, I have learnt about significant figures working within the field of categorical thinking, stigma and genetic diseases. I will even be attending an interesting lecture by Angela Saini on Anatomy of a myth: Why human classifications can't cure health disparities as a direct result of this project. I have built a network and become exposed to fields that I would like to do more research in.

3. Process

My prioritisation and time management was weak at the beginning of this project. I was not sure how to break my work down and ended up either not working at all or working for days at a time leading to burn out and stress and made tracking my progress harder. All the strategies I had put in place, including mini-deadlines, paced milestones and built-in breaks have helped me develop my project management. This was most likely the biggest gap in my leadership I observed but has allowed me to create plans to action this. These plans include prioritising each mini deadline as if they are their own standalone university assignments with strict deadlines from day one, rather than several weeks own the line.

Dissemination of research

This project's findings have been developed into a poster to condense and summarise its findings. This will allow for the project to be discussed and presented during the 2026 annual Laidlaw conference.

Looking beyond the conference, I would also like to share my work within university and other academic conferences.

Future career plans

My long-term goal is to become a genetic counsellor, and this project has only helped to reinforce this and has deepened my understanding of why I want to go into the field. Genetic

counselling includes all the things I have been writing about, the intersectionality of a patient's genetic information, their fears and social contexts. In the pursuit of trying to treat a diagnosis, the patients actual experiences can become obscured and disregarded. This is something I would ensure to avoid as a genetic counsellor.

This project has also helped me identify what sector of genetic counselling I would like to pursue. Engaging in cases like that of Shen'iyah Green has made my want to explore the paediatric side of genetic counselling more concrete. I want to be the person in the room who takes the parent concerns seriously and advocates for the patients' rights.

Finally, this project has deepened my genuine interest in continuing this line of research. If another opportunity comes around, I would love to further explore this project further. Maybe even by undertaking primary research with real patient testimony.

BIBLIOGRAPHY

Rees, D.C., Brousse, V.A.M. and Brewin, J.N. 2022. Determinants of severity in sickle cell disease. Blood Reviews. [Online]. **56**, article no: 100983. [no pagination] [Accessed 09 August 2026]. Available at: https://doi.org/10.1016/j.blre.2022.100983

Akinsheye, I., Alsultan, A., Solovieff, N., Ngo, D., Baldwin, C.T., Sebastiani, P., Chui, D.H.K. and Steinberg, M.H. 2011. Fetal hemoglobin in sickle cell anemia. Blood. [Online]. **118**(1), pp. 19-27. [Accessed 09 August 2026]. Available at: https://doi.org/10.1182/blood-2011-03-325258

Quinn, C.T. 2016. Minireview: Clinical severity in sickle cell disease: the challenges of definition and prognostication. Experimental Biology and Medicine. [Online] **241**(7), pp. 679-688. [Accessed 11 August 2026]. Available at: https://doi.org/10.1177/1535370216640385.

Hoffman, K.M., Trawalter, S., Axt, J.R. and Oliver, M.N. 2016. Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. Proceedings of the National Academy of Sciences of the United States of America. [Online]. **113**(16), pp. 4296-4301. [Accessed 11 August 2026]. Available at: https://doi.org/10.1073/pnas.1516047113.

Ola, B.A., Yates, S.J. and Dyson, S.M. 2016. Living with sickle cell disease and depression in Lagos, Nigeria: A mixed methods study. Social Science & Medicine (1982). [Online] **161**, pp. 27-36. [Accessed 15 August 2026]. Available at: https://doi.org/10.1016/j.socscimed.2016.05.029.

Dyson, S.M. and Atkin, K. eds. 2011. Sickle Cell Disease and the Social Sciences: Health, Racism and Disablement. [Online] London: Routledge. [Accessed 25 August 2026]. Available at: http://ebookcentral.proquest.com/lib/leeds/detail.action?docID=5741711.

Nelkin, D. and Lindee, M.S. 2004. The DNA Mystique: The Gene as a Cultural Icon. 2nd ed. Ann Arbor: University of Michigan Press.

National Institute for Health and Care Excellence (NICE). 2012. CG143: Sickle Cell Acute Painful Episode: Management of an Acute Painful Sickle Cell Episode in Hospital. [Online]. London: NICE. [Accessed 25 August 2026]. Available at: https://www.nice.org.uk/guidance/cg143

Sickle Cell Society and the All-Party Parliamentary Group on Sickle Cell and Thalassaemia. 2021. No One's Listening: An Inquiry into the Avoidable Death and Failures of Care for People with Sickle Cell Disease in Secondary Care. [Online]. London: Sickle Cell Society. [Accessed 25 August 2026]. Available at: https://www.sctsp.org.uk/post/no-ones-listening-report

NHS Race and Health Observatory. 2025. Sickle cell comparative review to inform policy report: Providing evidence-based recommendations to tackle inequalities. [Online]. London: NHS Race and Health Observatory. [Accessed 25 August 2026]. Available at: https://nhsrho.org/research/sickle-cell-comparative-research-to-inform-policy/

Cheng, S.H., Novelli, E.M., Kang, H.A., Newman, T.V. and Suh, K. 2026. Genotype differences and hydroxyurea utilization among adults with moderate to severe sickle cell disease. [Online]. Pharmacotherapy: The Journal of Human Pharmacology and Drug Therapy. **46**, article no: e70099. [no pagination]. [Accessed 15 August 2026]. Available at: https://doi.org/10.1002/phar.70099

Qureshi, A., Kaya, B., Pancham, S., Keenan, R., Anderson, J., Akanni, M. and Howard, J. 2018. On behalf of the British Society for Haematology 'Guidelines for the use of hydroxycarbamide in children and adults with sickle cell disease: A British Society for Haematology Guideline. [Online]. British Journal of Haematology. **181**(4), pp. 460-475. [Accessed 15 August 2026]. Available at: https://doi.org/10.1111/bjh.15235

Phillips, K., Healy, L., Smith, L. and Keenan, R. 2018. Hydroxyurea therapy in UK children with sickle cell anaemia: A single-centre experience. [Online]. Pediatric Blood & Cancer. **65**(1), pp. e26833. [Accessed 15 August 2026]. Available at: https://doi.org/10.1002/pbc.26833

BBC News. 2021. Evan Smith inquest: Hospital 'failure' led to sepsis patient's death. [Online]. [Accessed 09 August 2026]. Available at: https://www.bbc.co.uk/news/uk-england-london-56647361

Irvine, G. 2024. Dave Onawelo: Prevention of Future Deaths Report. [Online]. East London Coroner's Court. [Accessed 11 August 2026]. Available at: https://www.judiciary.uk/prevention-of-future-death-reports/dave-onawelo-prevention-of-future-deaths-report/

Goffman, E. 1963. Stigma: Notes on the Management of Spoiled Identity. Englewood Cliffs, NJ: Prentice-Hall.

Rohlfsen, C and Parsons S.A. The poverty of diagnostic essentialism: reimagining diagnosis in the age of artificial intelligence. [Online]. Diagnosis (Berlin, Germany). **13**(1), pp. 116–119. [Accessed 09 August 2026]. Available at: https://doi.org/10.1515/dx-2025-0081

Piel, F.B., Tewari, S., Brousse, V., Analitis, A., Font, A., Menzel, S., Chakravorty, S., Thein, S.L., Inusa, B., Telfer, P., de Montalembert, M., Fuller, G.W., Katsouyanni, K. and Rees, D.C. 2017. Associations between environmental factors and hospital admissions for sickle cell disease. [Online]. Haematologica. **102**(4), pp. 666-675. [Accessed 09 August 2026]. Available at: https://doi.org/10.3324/haematol.2016.154245

GBD 2021 Sickle Cell Disease Collaborators. 2023). Global, regional, and national prevalence and mortality burden of sickle cell disease, 2000–2021: a systematic analysis from the Global Burden of Disease Study 2021. [Online]. The Lancet Haematology. **10**(8), pp. e585-e599. [Accessed 11 August 2026]. Available at: https://doi.org/10.1016/S2352-3026(23)00118-7

Rees, D.C., Thein, S.L. and Weatherall, D.J. 2022. What does the term "sickle cell disease" mean? [Online]. British Journal of Haematology. **197**(3), pp. 381-382. [Accessed 11 August 2026]. Available at: https://doi.org/10.1111/bjh.18024.

NHS. 2022. Sickle cell disease. [Online]. [Accessed 25 August 2026]. Available at: https://www.nhs.uk/conditions/sickle-cell-disease