

RESEARCH PROPOSAL

A systematic review of barriers to healthcare access among adults with sickle cell disease in the United Kingdom

M.Sc Public Health and Social Care in Practice

Module: Practice-Based Research

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Research focus	Barriers to equitable healthcare access among Black African and Black Caribbean adults living with sickle cell disease in the UK.
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Final submission version

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Review design	Secondary research using a systematic review design, with transparent searching, screening, critical appraisal, data extraction and thematic synthesis.
Reporting framework	PRISMA 2020 will be used to support transparent reporting of the review. PRISMA-S principles will inform reporting of the literature search.

1. TITLE OF PROPOSED RESEARCH

A systematic review of barriers to healthcare access among adults with sickle cell disease in the United Kingdom.

2. PREVALENCE OF THE PROBLEM

Sickle cell disease (SCD) is one of the most common inherited blood disorders in the world, affecting millions of people and placing a considerable burden on individuals, families, and healthcare systems (Piel et al., 2017). In the United Kingdom, around 17,000 people are currently living with SCD, and approximately 250 babies are born with the condition each year in England (NHS England, 2023). In addition, the NHS Newborn Blood Spot Screening Programme identifies over 300 newborns with SCD annually, allowing early diagnosis and timely intervention (Public Health England, 2021).

SCD mainly affects people from African, Caribbean, Middle Eastern, Mediterranean, and South Asian communities (NHS England, 2023). In England, the condition is most common in London and other ethnically diverse urban areas, where the population includes a higher proportion of people from these backgrounds (NICE, 2021).

Although medical treatments and supportive care have improved over recent years, many adults living with SCD continue to experience difficulties when accessing appropriate healthcare services. Research has shown that patients often face delays in receiving pain relief, limited understanding of the condition among healthcare professionals, discrimination, stigma, and unequal access to specialist services (All-Party Parliamentary Group on Sickle Cell and Thalassemia, 2021; Tanabe et al., 2019). These challenges can result in poor disease management, frequent hospital admissions, preventable complications, and a reduced quality of life (Ware et al., 2017). Addressing healthcare inequalities for adults with SCD has therefore become an important UK health-policy concern.

3. INTRODUCTION AND LITERATURE-BASED BACKGROUND

Overview of Sickle Cell Disease

Sickle cell disease (SCD) is a genetic blood disorder inherited in an autosomal recessive pattern. It is caused by a mutation in the haemoglobin beta (HBB) gene, which leads to the production of an abnormal form of haemoglobin known as haemoglobin S (Rees et al., 2010). When oxygen levels are low, haemoglobin S causes red blood cells to change their normal flexible, disc-shaped form into rigid, sickle-shaped cells. These abnormal cells can block small blood vessels, reducing blood flow to different parts of the body. As a result, people with SCD may experience painful vaso-occlusive crises, chronic anaemia, progressive organ damage, and a shorter life expectancy (Gladwin and Vichinsky, 2008; Ware et al., 2017).

SCD is a lifelong condition with a wide range of clinical complications that can vary in severity between individuals. While recurrent episodes of severe pain are one of the most common features of the disease, many adults also develop long-term complications such as acute chest syndrome, stroke, kidney disease, and bone disorders (Makani et al., 2011). Because of these complex health needs, adults living with SCD require regular monitoring, access to specialist healthcare services, and ongoing treatment to manage symptoms, prevent complications, improve quality of life, and reduce the risk of premature death (Osunkwo et al., 2021).

Healthcare Access and Health Inequalities

Healthcare access refers to a person's ability to obtain appropriate healthcare services when they are needed in order to achieve the best possible health outcomes (Penchansky and Thomas, 1981). It involves factors including service availability, accessibility, organisation, affordability and acceptability. Equitable access is important for reducing health inequalities and improving health and wellbeing.

Within the UK National Health Service (NHS), fair access to healthcare is recognised as a key principle of health equity. Evidence nevertheless indicates that some groups, particularly people from ethnic minority backgrounds and people living with long-term conditions, continue to face barriers when accessing healthcare services. Adults living with SCD are among those affected by these inequalities.

Barriers to Healthcare Access in Sickle Cell Disease

Barriers may occur at individual, healthcare-provider and healthcare-system levels and can interact with one another.

Level	Examples of barriers
Individual	Limited health literacy, financial difficulties, transport problems, awareness of services, anxiety, depression and emotional distress.
Healthcare provider	Limited SCD knowledge, stigma, racial bias and negative assumptions about opioid-seeking during pain crises.
Healthcare system	Inconsistent specialist services, fragmented care, inadequate coordination and delays in recognising and treating vaso-occlusive crises.

Patients may report stigma, racial bias and negative assumptions that they are seeking opioids rather than treatment for genuine pain crises. These misconceptions can contribute to delays in pain relief and reduced trust in healthcare services (Tanabe et al., 2019). At system level, fragmented care and poor coordination between services may further affect timely access. Evidence from the National Confidential Enquiry into Patient Outcome and Death (2021) identified shortcomings in the delivery of SCD care, including delays in treatment and clinical-management failures.

Rationale for the Systematic Review

Although individual studies have explored different barriers to healthcare access, the evidence remains dispersed. A systematic review can identify, critically evaluate and synthesise the available evidence, helping to clarify recurring barriers, identify gaps, and inform practice and policy.

4. RATIONALE AND RESEARCH QUESTION / AIMS

Rationale

Sickle cell disease predominantly affects people of Black African and Black Caribbean heritage in the UK. Although national policies and clinical guidance aim to promote equitable healthcare, adults living with SCD may continue to experience barriers associated with service organisation, treatment experiences, discrimination, unconscious bias and wider structural inequalities. These experiences may contribute to delays in treatment, inadequate pain management, reduced trust in healthcare professionals and negative healthcare experiences.

Research Question

Primary question	What are the barriers to equitable healthcare access among adults of Black African and Black Caribbean ethnicity living with sickle cell disease in the UK?
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Research Aim

To systematically review and synthesise evidence on barriers to equitable healthcare access among adults of Black African and Black Caribbean ethnicity living with sickle cell disease in the United Kingdom.

Research Objectives

- To identify the main barriers that affect equitable healthcare access among adults of Black African and Black Caribbean ethnicity living with sickle cell disease in the UK.
- To examine patient-related, provider-related and system-level factors that influence healthcare access, including experiences of ethnic discrimination and racism.
- To evaluate the reported impact of healthcare access barriers on health outcomes and quality of life among Black African and Black Caribbean adults with sickle cell disease.
- To identify interventions and recommendations reported in the literature for improving equitable healthcare access for Black African and Black Caribbean adults with sickle cell disease.

5. RESEARCH METHODOLOGY

A secondary research methodology using a systematic review approach will be employed. The review will identify, critically evaluate and synthesise evidence from existing published studies exploring barriers to equitable healthcare access among adults of Black African and Black Caribbean ethnicity living with SCD in the UK.

The review will use a structured and reproducible process covering literature searching, screening, eligibility assessment, critical appraisal, data extraction and thematic synthesis. The methodological approach will be informed by established systematic-review guidance, including the Cochrane Handbook.

Reporting

PRISMA 2020 will be used to support transparent reporting of the review. The search strategy and reporting of information sources will also be informed by PRISMA-S, an extension focused on reporting literature searches.

Important distinction	PRISMA 2020 is a reporting guideline rather than a research design. The research design in this proposal is a systematic review of secondary evidence.
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6. RESEARCH DESIGN

The study will use a systematic review design based on secondary research. The review will follow a predefined sequence of literature searching, screening, eligibility assessment, quality appraisal, data extraction and thematic synthesis.

Review Population

Published research concerning adults aged 18 years and over with sickle cell disease, with an explicit focus on Black African and/or Black Caribbean populations or relevant ethnic health inequalities in the UK.

Review Process

Search results will be screened by title and abstract, followed by full-text assessment against predefined criteria. Reasons for exclusion at the full-text stage will be documented. A PRISMA-style flow diagram will be prepared for the completed review; no numerical results are presented at proposal stage.

7. SEARCH STRATEGY AND STUDY SELECTION

Information Sources

The following databases and information sources will be searched systematically:

- PubMed/MEDLINE
- CINAHL
- Scopus
- Web of Science
- Google Scholar

Search Concepts

Search terms will be combined using Boolean operators and adapted to each database. Core concepts will include:

- sickle cell disease
- healthcare access
- health inequalities
- barriers
- Black African
- Black Caribbean
- United Kingdom
- health equity

Inclusion Criteria

- Adults aged 18 years and over with a confirmed diagnosis of sickle cell disease.
- Studies conducted in the United Kingdom.
- Studies published in English.
- Peer-reviewed research articles with relevant empirical data.
- Studies examining barriers or facilitators to healthcare access.
- Studies with an explicit focus on Black African and/or Black Caribbean populations or relevant ethnic health inequalities.
- Studies published between 2014 and 2026, subject to final search results and eligibility assessment.

Exclusion Criteria

- Studies involving children only, where adult findings cannot be separated.
- Non-English publications.
- Studies conducted outside the UK.
- Opinion pieces, editorials, commentaries or publications without relevant research data.
- Studies examining other blood disorders without a specific focus on SCD.

8. QUALITY APPRAISAL

The Critical Appraisal Skills Programme (CASP) Qualitative Checklist will be used to assess the methodological quality and rigour of included qualitative studies. The appraisal will consider the clarity of the research question, appropriateness of design, recruitment, data collection, relationship between researcher and participants, ethical considerations, analytical process and clarity of findings.

Quality appraisal will not be used simply as a mechanism to remove studies; rather, the appraisal findings will inform interpretation of the strength and limitations of the evidence base. Appraisal decisions will be documented transparently.

9. DATA EXTRACTION AND SYNTHESIS

Data Extraction

Data will be extracted using a standardised extraction form. The following information will be recorded where available:

- Author and publication year.
- Study design and methodology.
- Sample characteristics and setting.
- Relevant population and UK context.
- Barriers and facilitators identified.
- Main findings and themes.
- Reported impacts on healthcare access and outcomes.
- Recommendations for practice, policy or further research.

Data Synthesis

A thematic synthesis approach will be used to identify patterns, themes and concepts across the included studies. Findings will be organised around patient-related, healthcare-provider and healthcare-system barriers, while also considering ethnicity, discrimination, cultural factors and health equity.

The final number of included studies will be determined by the search and screening process. No final study count will be claimed at proposal stage.

10. ETHICAL CONSIDERATIONS

Ethical Position

This proposal concerns a systematic review of published literature and does not involve direct recruitment, interviews, biological samples or primary participant data collection. Participant consent is therefore not applicable to the review itself. The researcher will comply with the university's research ethics, academic-integrity and governance requirements and obtain any institutional approval required before the review begins.

Research Integrity and Data Management

Search records, screening decisions, extraction forms and review notes will be stored securely in accordance with university requirements. The review will report methods and decisions transparently, avoid selective reporting, maintain accurate citations, and acknowledge limitations and uncertainty in the evidence.

Researcher Reflexivity

The researcher will reflect on assumptions and potential bias when interpreting evidence concerning ethnicity, racism, discrimination and healthcare inequalities. Supervision will be used to support methodological consistency and critical reflection.

11. IMPLICATIONS OF RESEARCH

Clinical Practice and Policy

The review may provide evidence to support improvements in clinical practice, service organisation and healthcare policy. Understanding barriers experienced by Black African and Black Caribbean adults with SCD may help healthcare professionals respond more effectively to patient needs and identify areas for culturally responsive and equitable care.

Health Equity and Social Justice

By synthesising evidence concerning healthcare access and ethnic health inequalities, the review may contribute to a clearer understanding of how discrimination and structural inequalities influence healthcare experiences and access.

Future Research

The review may identify gaps in the evidence base and inform future research priorities, including evaluation of interventions intended to improve access, reduce inequalities and address barriers at individual, organisational and system levels.

12. PLAN OF WORK AND TIME SCHEDULE

The systematic review and dissertation will be conducted over a 16-week period. The schedule below directly addresses the tutor feedback by explicitly incorporating the planned writing of the dissertation chapters alongside searching, screening, appraisal, synthesis, revision and final submission.

Task / Activity	W1	W2	W3	W4	W5	W6	W7	W8	W9	W10	W11	W12	W13	W14	W15	W16
Finalise proposal, ethics & protocol	●															
Chapter 1 – Introduction		●	●													
Chapter 2 – Literature Review			●	●												
Database searching / search strategy			●	●												
Title & abstract screening					●											
Chapter 3 – Methodology					●	●										
Full-text screening & eligibility						●										
Data extraction							●	●								
Quality appraisal								●								
Data synthesis / analysis									●	●						
Chapter 4 – Results / Findings										●	●					
Chapter 5 – Discussion												●	●			
Conclusion & Recommendations														●		
Revision, proofreading & finalisation															●	
Final dissertation submission																●

TABLE 1. Proposed 16-week systematic review and dissertation schedule

Tutor feedback addressed	Chapter 1 – Introduction, Chapter 2 – Literature Review, Chapter 3 – Methodology, Chapter 4 – Results/Findings, Chapter 5 – Discussion, and Conclusion/Recommendations are now explicitly scheduled.
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13. REFERENCES

- All-Party Parliamentary Group on Sickle Cell and Thalassemia (2021) *No One's Listening: An Inquiry into the Avoidable Deaths and Failures of Care for Sickle Cell Patients in Secondary Care*. London: APPG.
- Braun, V. and Clarke, V. (2013) *Successful Qualitative Research: A Practical Guide for Beginners*. London: SAGE.
- Cooke, A., Smith, D. and Booth, A. (2012) 'Beyond PICO: The SPIDER tool for qualitative evidence synthesis', *Qualitative Health Research*, 22(10), pp. 1435–1443.
- Department of Health and Social Care (2022) *Health Disparities White Paper*. London: DHSC.
- Gladwin, M.T. and Vichinsky, E. (2008) 'Pulmonary complications of sickle cell disease', *New England Journal of Medicine*, 359(21), pp. 2254–2265.
- Higgins, J.P.T., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page, M.J. and Welch, V.A. (eds) (2026) *Cochrane Handbook for Systematic Reviews of Interventions*, Version 6.5.1. Cochrane.
- Makani, J., Williams, T.N., Marsh, K. et al. (2011) 'Mortality in sickle cell disease in Africa: A prospective cohort study in Tanzania', *PLoS ONE*, 6(2), e14699.
- National Confidential Enquiry into Patient Outcome and Death (2021) *The In-Hospital Management of Adults with Sickle Cell Disease*. London: NCEPOD.
- National Institute for Health and Care Excellence (2012, updated 2023) *Sickle Cell Disease: Managing Acute Painful Episodes in Hospital (CG143)*. London: NICE.
- NHS England (2023) *Sickle Cell and Thalassemia Programme*. London: NHS England.
- Nnadi, N.C. and Beyerl, B. (2010) 'Opioid use in patients with sickle cell disease: A review of the evidence', *Journal of Pain and Symptom Management*, 40(4), pp. 557–566.
- Office for Health Improvement and Disparities (2022) *Health Inequalities: Place-Based Approaches to Reduce Inequalities*. London: OHID.
- Osunkwo, I., Andemariam, B., Minniti, C.P. et al. (2021) 'Impact of sickle cell disease on patients' daily lives, health and healthcare experiences', *Blood Advances*, 5(15), pp. 3018–3029.
- Page, M.J., McKenzie, J.E., Bossuyt, P.M. et al. (2021) 'The PRISMA 2020 statement: An updated guideline for reporting systematic reviews', *BMJ*, 372, n71.
- Penchansky, R. and Thomas, J.W. (1981) 'The concept of access: Definition and relationship to consumer satisfaction', *Medical Care*, 19(2), pp. 127–140.
- Piel, F.B., Steinberg, M.H. and Rees, D.C. (2017) 'Sickle cell disease', *New England Journal of Medicine*, 376(16), pp. 1561–1573.
- Public Health England (2021) *NHS Newborn Blood Spot Screening Programme: Standards and Guidelines*. London: PHE.
- Rees, D.C., Williams, T.N. and Gladwin, M.T. (2010) 'Sickle-cell disease', *The Lancet*, 376(9757), pp. 2018–2031.
- Rethlefsen, M.L., Kirtley, S., Waffenschmidt, S. et al. (2021) 'PRISMA-S: An extension to the PRISMA statement for reporting literature searches in systematic reviews', *Systematic Reviews*, 10, 39.
- Royal College of Nursing (2021) *Caring for People Living with Sickle Cell Disease*. London: RCN.
- Spratling, R., Tanabe, P., Treadwell, M., Hankins, J.S., Raphael, C.K. and Nolan, V.G. (2019) 'Barriers to management of acute pain in sickle cell disease', *International Journal of Nursing Studies*, 78, pp. 134–141.
- Tanabe, P., Spratling, R., Smith, D., Grissom, P. and Hulihan, M. (2019) 'CE: Understanding the complications of sickle cell disease', *American Journal of Nursing*, 119(6), pp. 26–35.
- Treadwell, M.J., Hassell, K.L., Levine, R., Kleman, K. and Rovi, S. (2011) 'Adult sickle cell disease patient knowledge of the complications of sickle cell disease', *Journal of the National Medical Association*, 103(5), pp. 355–363.
- Ware, R.E., de Montalembert, M., Tshilolo, L. and Abboud, M.R. (2017) 'Sickle cell disease', *The Lancet*, 390(10091), pp. 311–323.
- World Health Organization (2023) *Sickle-cell Disease: A Public Health Approach*. Geneva: WHO.