SICKLE CELL SOCIETY

NHS
RACE & HEALTH
OBSERVATORY

Sickle cell comparative review to inform policy report

Providing evidence-based recommendations to tackle inequalities

June 2025

IMPERIAL

Foreword

Sickle cell is the most common genetic disorder in the UK, yet it has endured years of inadequate attention and investment, resulting in stark and persistent inequalities in healthcare for those living with the condition. This detailed research is invaluable in pinpointing where discrimination and bias continue to occur—whether in resource allocation, access to specialist care, or research funding. Crucially, the findings reveal that this neglect is not due to a lack of need: hospital admissions for sickle cell rose by 42% between 2013 and 2022.

The report goes beyond identifying disparities. It uncovers the root causes of these inequalities and offers an evidence-based foundation for meaningful change. It highlights a long-standing pattern of underinvestment and de-prioritisation that has eroded trust among many people with sickle cell in the healthcare system. Too often, they encounter poor knowledge of their condition or substandard treatment from the very services designed to support them.

In this context, the report is more than just a call to action – it is a roadmap for change. Its six key recommendations for policy, practice, and research provide actionable, practical solutions aimed at addressing the systemic failures exposed. If adopted, these measures could improve outcomes, rebuild trust, and ensure that people with sickle cell across the country receive the care that they need and deserve.

Moreover, this comparative research holds lessons that extend beyond sickle cell care. By examining disparities in funding and resource allocation compared to conditions such as cystic fibrosis and haemophilia, the report identifies both areas of progress and opportunities for improvement across multiple conditions. It demonstrates the impact of sustained investment in specialist care. The goal is to learn from gains made in other conditions in order to raise the standard of care for people with sickle cell to the same level – ensuring equity.

We extend our sincere gratitude to the research team, the advisory group, and the many experts and key partners who contributed to this vital work. Special thanks go to the people with sickle cell, their families, nurses, and haematologists across the NHS, whose lived experiences and insights have enriched the report's technical rigour and practical relevance. Their voices remind us why change is not only necessary but urgent.

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Executive summary

Sickle cell is often described as a neglected disease, both globally and in the UK. Comparative research can provide valuable insights into inequalities to guide public health policies. In this report, we analysed data across a wide range of indicators, by i) reviewing the literature and previous reports; ii) looking at research funding, financial resources of charities, scientific publications, clinical trials, approved drugs, dedicated disease registries and online awareness for sickle cell, cystic fibrosis and haemophilia; iii) analysing hospital admission data for these three conditions in relation to waiting times, length of hospital stays and estimated costs to the NHS; and iv) collecting evidence from patients about their lived experiences to complement the other parts of our analyses.

Some of our data reveals striking inequalities, which were often reflected in the experiences of patients living with sickle cell across the country. Nevertheless, evidence of these inequalities is not new, and this report adds further to the urgent need to address the underlying problems affecting the quality of care for patients with sickle cell. Importantly, this comparative research shows that improvements are also needed for other severe chronic conditions, such as cystic fibrosis and haemophilia, and that lessons can be learned from successes achieved in other specialties. This report includes a set of recommendations that aim to help tackle inequalities associated with sickle cell in the UK.

Graphic summary of findings

20%
of babies with **sickle cell** were not seen by a specialist by three months of age

42%
increase in hospital admissions for **sickle cell** between 2013 and 2022

Total estimated annual hospitalisation costs
2X HIGHER
for **sickle cell** than **cystic fibrosis**

The median age of death for

sickle cell **47**

cystic fibrosis **46**

general population **84**

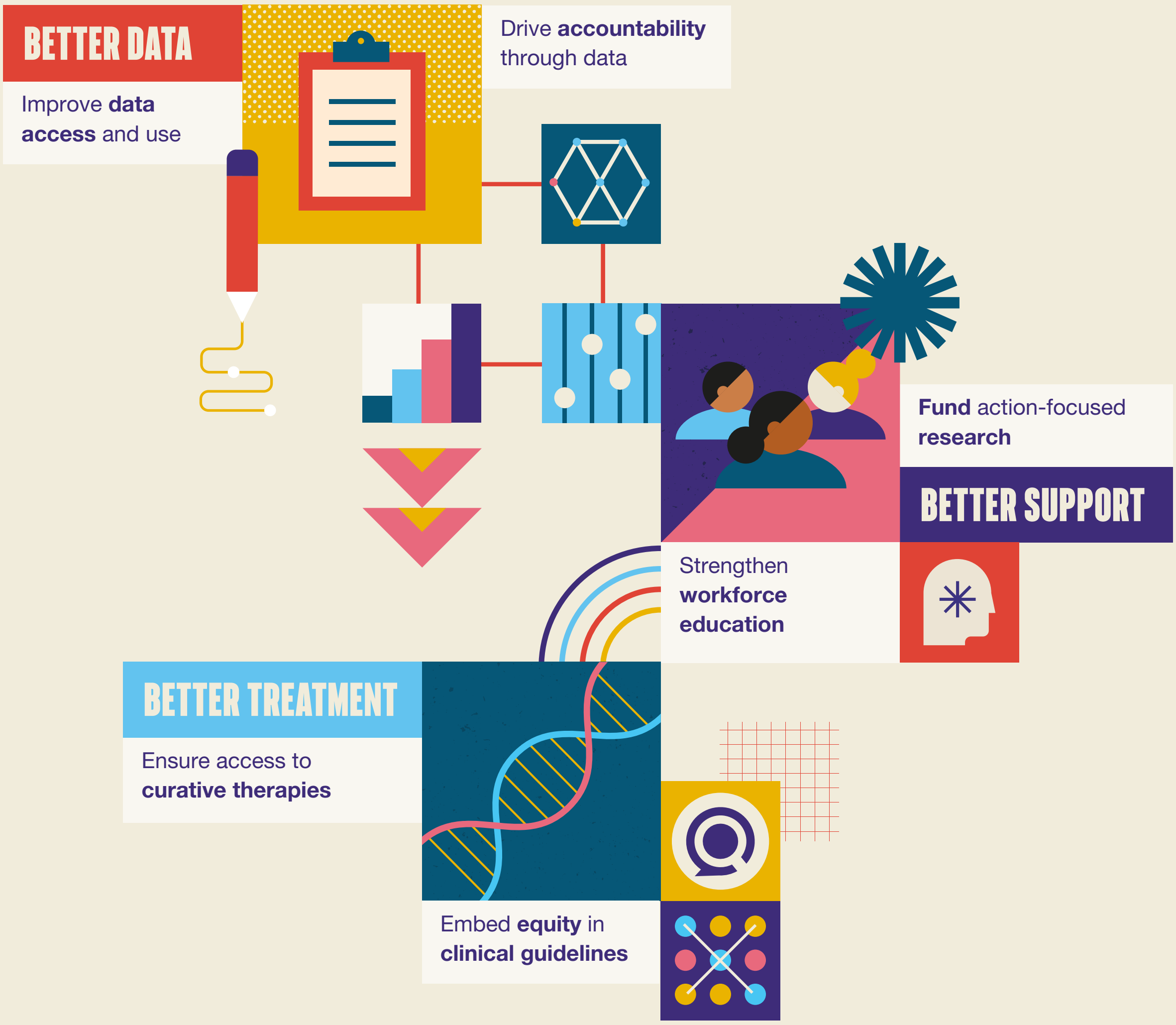
~2
specialist nurses per 100 patients for **cystic fibrosis** vs
~0.5
for **sickle cell**

>2.5X
more research funding for **cystic fibrosis** than for **sickle cell** or **haemophilia**

On average, patients with **sickle cell** managed
7 PAIN CRISES
without medical help

In a multi-country study, people with **sickle cell** in the UK had the **highest** annual mean hospitalisations for pain crises

Graphic summary of recommendations



BETTER DATA

Improve **data access** and use

Drive **accountability** through data

BETTER SUPPORT

Fund action-focused **research**

Strengthen **workforce education**

BETTER TREATMENT

Ensure access to **curative therapies**

Embed **equity** in **clinical guidelines**

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