

London Sickle Cell Improvement Programme

Why was the programme set up?

1 Disproportionate impact on African and Caribbean communities

Sickle cell disorder is a lifelong inherited condition, affecting the red blood cells, causing them to be a different shape. This can result in blockages in blood vessels. The disorder primarily affects people from African and Caribbean backgrounds, although it can impact anyone. The most prevalent symptoms are anaemia, painful episodes (known as *crises*), and increased risk of serious infections ([NHS, 2022](#)).



2 Mistakes made in care

In 2019, Evan Nathan Smith, a 21-year-old man with sickle cell disorder tragically died whilst in hospital. The subsequent inquest found shortcomings in his care, contributing to his untimely passing. This led to the publication of the No One's Listening report ([SCTAPPG, 2021](#)).



3 The No One's Listening report

The report details the substantial evidence found for inadequate care in hospital wards and emergency departments, including a concerning pattern of negative attitudes towards people with sickle cell disorder, with evidence implying that these attitudes often stemmed from racial biases and a lack of awareness of sickle cell disorder, limited education and insufficiency of resources for sickle cell care.



4 Mistrust in the healthcare system

People living with sickle cell disorder have therefore lost trust in the healthcare system, making them apprehensive to seek care. They fear poor treatment by healthcare staff and their lack of sickle cell disorder knowledge. The report's findings demonstrate the significant health inequalities faced by patients with sickle cell disorder and the need for change ([APPG, 2021](#)).



5 NHS England sickle cell priority and programme

Following the recommendations in this report, NHS England established a sickle cell work programme, highlighting 10 quality improvement actions. In addition, the NHS England team in London worked with integrated care systems in the capital, identifying sickle cell disorder as one of three priority pathways for improvement.



6 London Sickle Cell Improvement Programme

The London Sickle Cell Improvement Programme seeks to improve sickle cell services across all settings of care – integrating patient health records into a London wide digital care plan, increasing support in the community and investing in urgent and emergency pathways to improve care, experience and outcomes for those living with sickle cell disorder in London.

