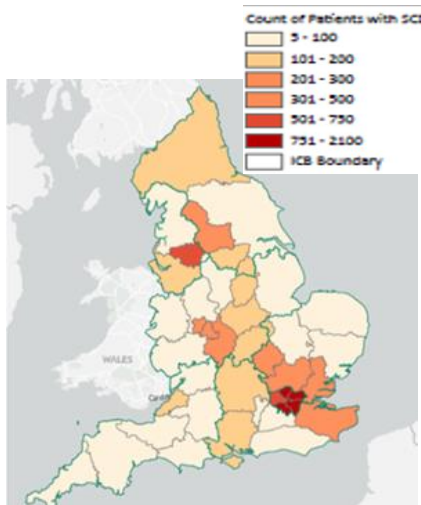


# Sickle cell disease – proactive care and UEC pathway transformation



Geographic Spread of persons with SCD in England

2. Every ICS has registered patients – ranging from <10 – 2056, but the highest prevalence areas are South East London, Birmingham and Manchester due ethnically diverse populations.

52% of all SCD patients are registered with a London GP and 300 babies are born with SCD each year.



1. SCD is the most common genetic condition in England, with 17,000 people living with the condition. It is a serious and potentially life limiting condition and predominantly occurs in people of Black ethnicity.

3. People with SCD have extremely painful episodes called sickle cell crises, which can be very severe and last up to a week.



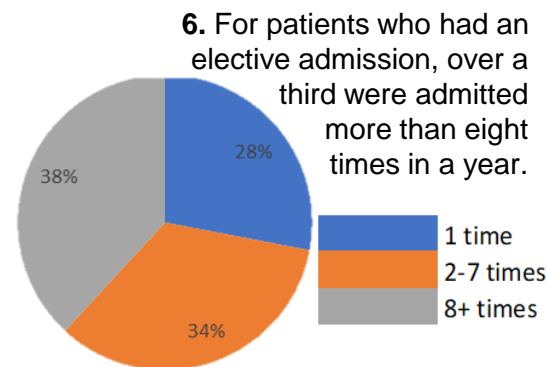
5. Because of frequent sub-standard care and poor experiences with ambulance and A&E, people with SCD in crisis avoid seeking professional help for as long as possible. However, there are an average of 22,000 UEC contacts per year:

- In London, 50% of patients report accessing A&E in the past 6 months. This fluctuates seasonally with lower temperatures associated with increased need.
- 45% of the UEC episodes are by patients in the most deprived CORE 20 population
- People aged 20-39 years account for 35% of patients but 46% of the UEC contacts.
- 60% of the UEC contacts are classified as requiring immediate, very urgent or urgent care

The NHS Race Observatory was commissioned to examine the impact of racist attitudes and the extent of inequalities in funding and prioritisation. In January 2023 they reported to have found sickle cell crisis pain is deprioritised and undermined – with sub-optimal pain management and frequent failures to give timely analgesia; patients are exposed to racist attitudes and an extreme lack of empathy and compassion, accountability to treating people with SCD is lacking, avoidable harm and death has occurred to patients and that these issues are ‘extremely widespread’.

4. People with SCD have historically experienced significant clinical care failings which have resulted in the death of patients. This is detailed in the No One’s Listening Report, published by the APPG in Nov 21.

The APPG commissioned the No One’s Listening Report following the Inquest of the death of Evan Nathan Smith. Evan was a 21 year old man who died in hospital on 25<sup>th</sup> April 2019. The Inquest heard, that at one point while being treated in hospital, Evan was so desperate for help that he rang 999 from his mobile phone to ask for oxygen because he was refused this by a nurse on his ward.



6. For patients who had an elective admission, over a third were admitted more than eight times in a year.

7. People with SCD account for 103,000 outpatient contacts per year, however the NHS does not reliably provide adequate support to SCD patients to access disease modifying therapies that can reduce crisis frequency.



8. These poor experiences don’t help patients adhere to treatment or encourage patient self management. They similarly diminish trust and engagement and ultimately lead to poorer health outcomes.

**There is significant opportunity to address these issues and inequalities. It is proposed to invest in piloting a new model of care over 2 years.**