One Lambeth

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Health Intelligence sickle cell disorder update

February 2025

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Information

Purpose of update

Based on available data, this update provides access to information and intelligence to support commissioners, Public Health directors and others involved in the local planning and provision of services and interventions. The factsheet presents the data and doesn't seek to give reasons for any association or causation.

Why we use data

We use data to understand and tackle health inequalities because it helps us see who is affected the most and why. By gathering and analysing data, looking at characteristics like age, sex, gender, sexual orientation, disability and socioeconomic status, we can uncover patterns and trends that show where people are facing health challenges.

In some cases, data is not available for every characteristic or data cannot be published due to small numbers and confidentiality. Taking this into consideration when looking at the data, forward planning and work programmes are created to address these gaps and inequalities to ensure everyone has a fair chance at good health.

Data is crucial for shining a light on inequalities and guiding efforts to make healthcare more equitable for everyone, regardless of their background or circumstances.

Introduction

300 babies born in the UK with sickle cell disorder each year

Sickle cell disorder is a group of inherited blood disorders that cause red blood cells (RBCs) to become sickle-shaped, rigid, and sticky instead of being round and flexible. This abnormal shape is caused by a mutation in the RBC protein haemoglobin. SCD can block blood flow, reduce oxygen delivery, and lead to painful episodes and organ damage. The most severe form of SCD is sickle cell anaemia (SCA). **Anyone can be affected by sickle cell disorder.**

People with sickle cell trait (SCT) inherit a sickle haemoglobin (Hb S) gene from one parent and a normal haemoglobin gene from the other. **Carriers of SCT rarely have symptoms**.

Individuals with SCT have a 1 in 2 chance of passing the sickle cell gene to their children. If both parents have SCT, there is a 1 in 4 chance their child will be born with sickle cell disease.

1 in 79 babies born in the UK carry SCT

17,500 people with sickle cell disease in the UK

Individuals with two clinically significant abnormal haemoglobin genes will have sickle cell disease.

A person with two copies of the Hb S gene has homozygous sickle cell disease, better known as SCA.

A person who has one Hb S gene and one copy of another clinically significant abnormal haemoglobin gene (such as Hb C, D, O, E, or Lepore) has clinically significant heterozygous SCD. This can include Sickle Beta-Thalassemia , when a person has one Hb S gene and a mutated version of the beta-thalassemia gene; beta-thalassemia reduces haemoglobin production.

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More information can be found on the NICE health topic : Sickle Cell Disease

Symptoms of SCD

Cold weather, dehydration, stress, strenuous exercise can be triggers for crises

Sickle cell crises are the most common and distressing symptoms of sickle cell disorder. **The sickle-shaped, sticky red blood cells (RBCs) can block blood flow in vessels leading to pain for days or even weeks which can require morphine**. The frequency of these pain episodes varies significantly; some people experience them frequently, while others may have them less than once a year.

People with sickle cell disorder are more susceptible to infections, particularly in childhood. These infections can range from common colds to more serious, life-threatening conditions like meningitis. The risk of infection can be reduced through vaccinations and daily antibiotics.

Complications of sickle cell disorder include stroke, blindness, and bone damage

Over time sickle cell disorder can damage liver, kidney, lungs, heart, and spleen

Nearly everyone with sickle cell disorder experiences anaemia due to low haemoglobin levels in the blood. This reduction in RBCs can lead to symptoms such as headaches, rapid heartbeat, dizziness, and fainting.

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https://www.sicklecellsociety.org/about-sickle-cell/

Sickle cell prognosis

Variable severity; unpredictable onset of crises

The general UK life expectancy is 79 years for males and 83 years for females

Median survival for sickle cell patients in the UK is 67 years : 50% of patients live beyond 67

More than 90% of UK sickle cell patients survive past 20, significant numbers older than 50

In the UK 99% affected children survive to adulthood

People with frequent pain episodes are more likely to die earlier

Chronic organ damage results in many medical complications

Long-term complications include stroke, renal failure, and hypertension

Acute crisis is pain caused by blocked blood vessels

Acute complications include anaemia, infections, kidney injury

Chronic complications like pain, anaemia, liver problems, respiratory problem affect quality of life

Complications in pregnancy include perinatal mortality, premature labour, fetal growth restriction, and acute painful crises.

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More information can be found at NICE

Setting the national scene

Sickle cell is a significant issue for clinical practice worldwide

In England approximately 660k pregnant women were screened (2019-2020)

In England approximately 620k newborn babies screened (2019-2020)

In England 1 in 2500 babies tested positive for sickle cell disorder, 1 in 77 were carriers (2019-2020)

In London approximately 135k pregnant women were screened (2019-2020)

In London approximately 122k newborn babies screened (2019-2020)

In London 1 in 970 babies tested positive for sickle cell disorder, 1 in 35 were carriers (2019-2020)

London has the most people with sickle cell disorder in England

1 in 4 of those people with sickle cell disorder live in South London

700 registered patients with sickle cell disorder in Lambeth

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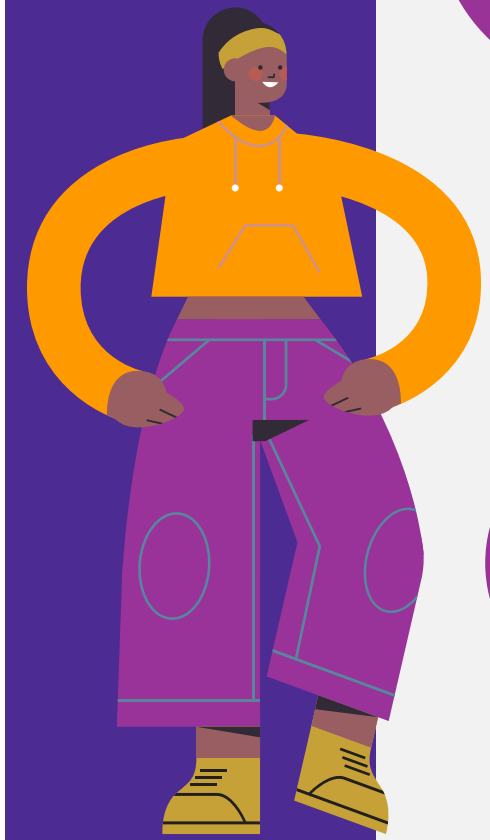
NICE Health Topics - Sickle cell disease
SE London ICS - sickle cell

Sickle cell in the Lambeth registered GP population

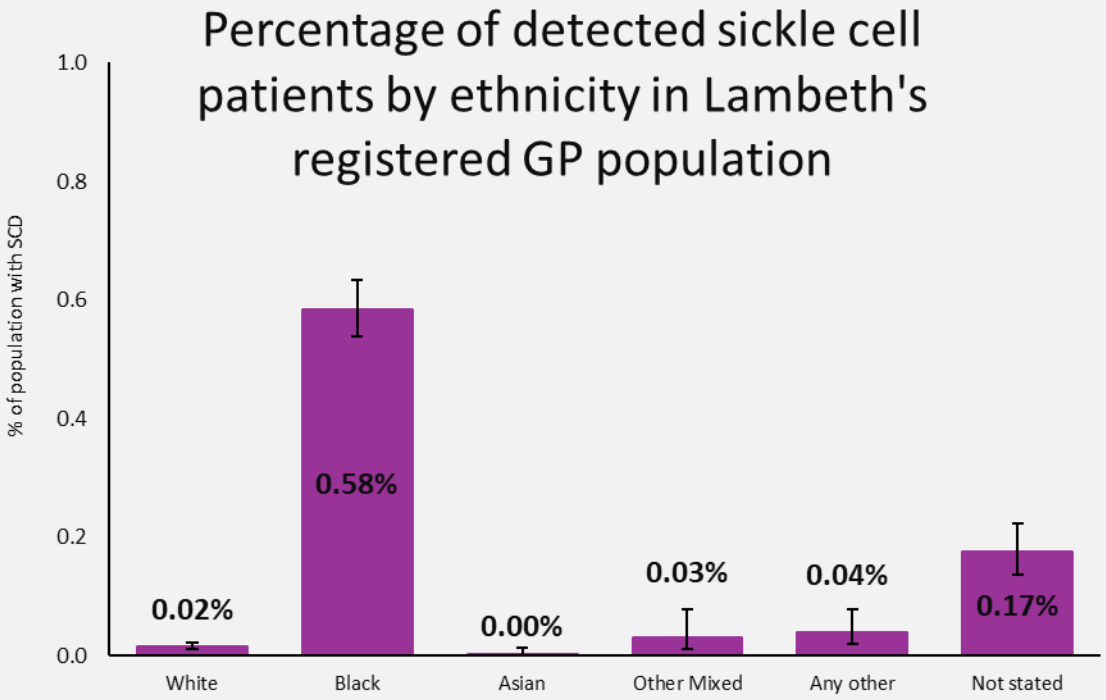


420k people in Lambeth registered GP population : 700 patients with sickle cell in Lambeth

Detected sickle cell prevalence 32 times higher in Black population than other ethnic groups

80% of the Lambeth registered GP population with sickle cell in Lambeth are Black

20% of the Lambeth registered GP population are Black



Ethnic Group	Registered patients	Diagnosed Sickle Cell	Percentage of population group with SCD (%)
White	219,816	36	0.02
Black	98,886	577	0.58
Asian	38,382	<10	0.00
Other Mixed	13,061	<10	0.03
Any other	20,258	<10	0.04
Not stated	36,031	63	0.17

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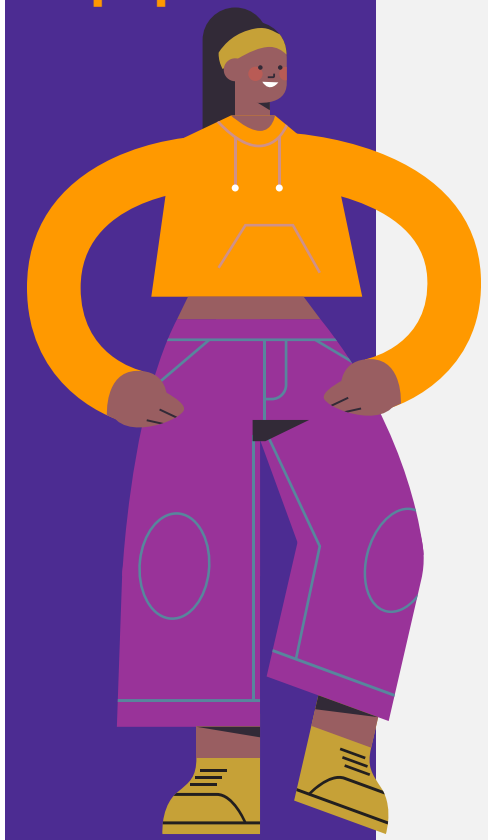
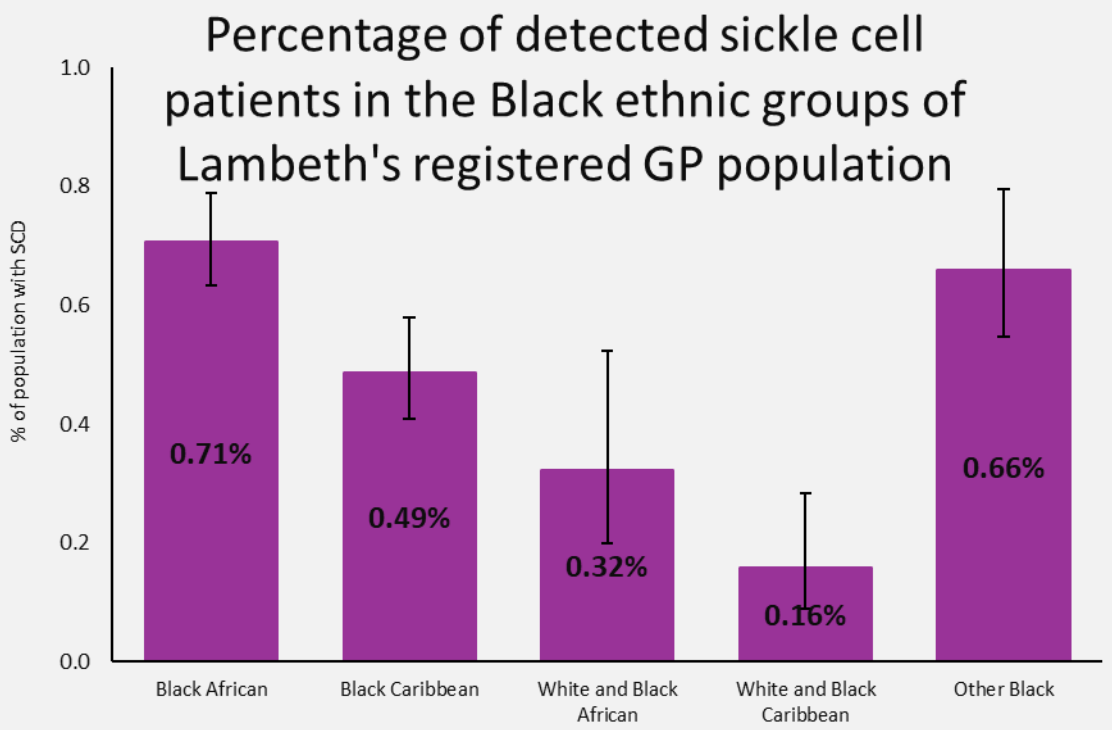
Sickle cell in the Black ethnic groups of Lambeth's GP population



577 patients in the registered GP population of Lambeth who are of Black heritage.

Highest detected prevalence is in Black African population

Black African SCD population is larger than all other groups combined



Ethnic Group	Registered patients	Diagnosed Sickle Cell	Percentage of population group with SCD (%)
Black African	44747	316	0.71
Black Caribbean	25854	126	0.49
White and Black African	4959	16	0.32
White and Black Caribbean	6933	11	0.16
Other Black	16393	108	0.66

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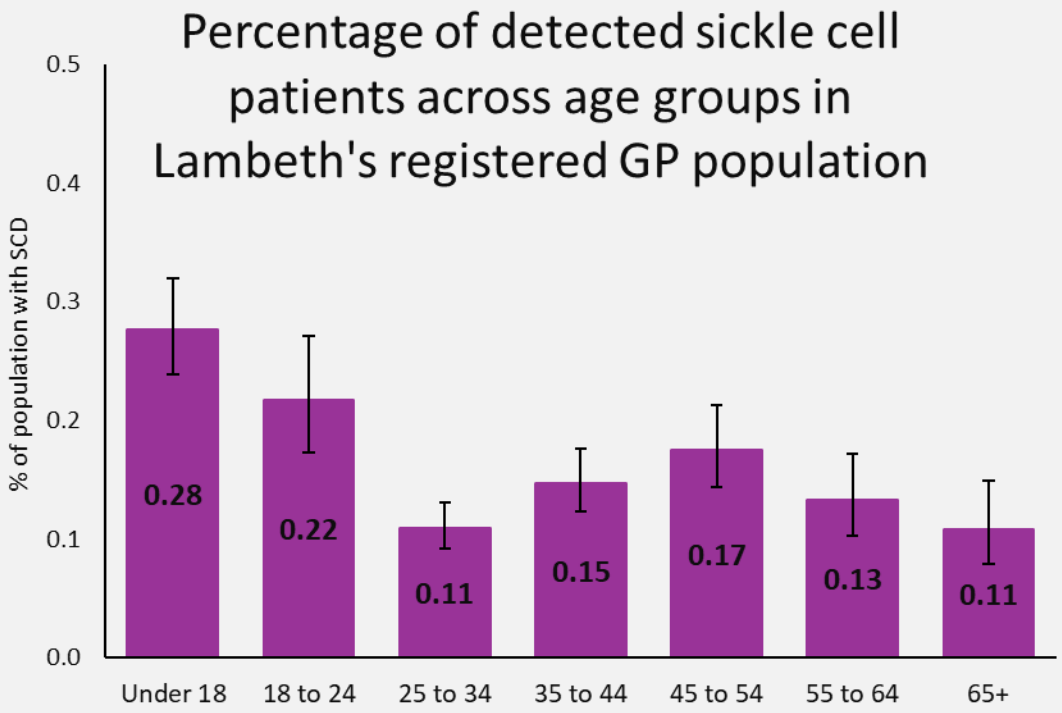
Sickle cell in the different age groups of Lambeth's registered GP population

Highest proportion of detected cases is in the Under 18 cohort

Number of detected cases drops off in those 55+ years old

1 in 4 SCD patients in Lambeth are Under 18

1 in 3 SCD patients in Lambeth are aged 25 - 44



Lambeth registered GP population	Under 18	18 to 24	25 to 34	35 to 44	45 to 54	55 to 64	65+
Registered patients	64742	34594	111456	81701	56002	42936	35003
Diagnosed Sickle Cell	179	75	122	120	98	57	38
Percentage of population group with SCD (%)	0.28	0.22	0.11	0.15	0.17	0.13	0.11

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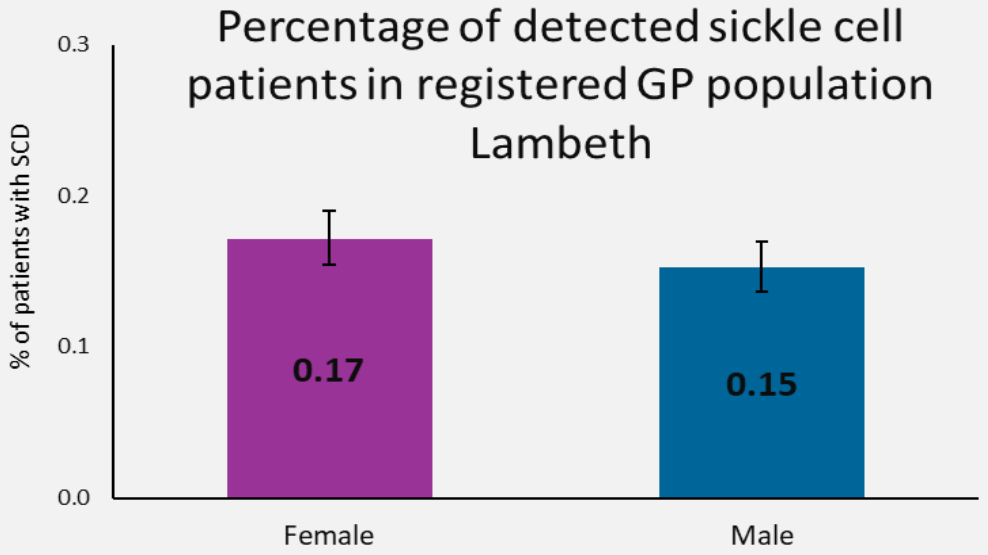
Lambeth's sickle cell population – gender

358 registered female patients with sickle cell in Lambeth

331 registered male patients with sickle cell in Lambeth



Lambeth registered GP population	Females	Males
Registered patients	209209	217197
Diagnosed sickle cell	358	331
Percentage of population group with SCD (%)	0.17	0.15

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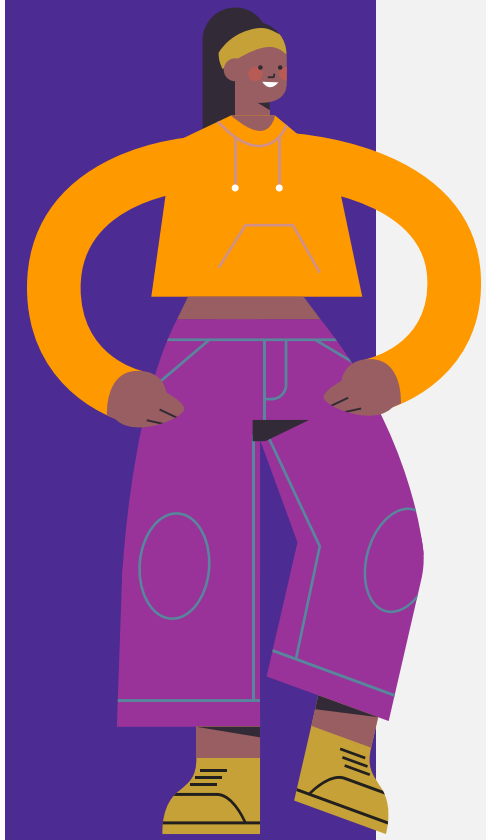
Data sources used



This update makes use of anonymised data held in Lambeth Datanet.

Lambeth DataNet helps improve healthcare in Lambeth by using anonymous GP patient data. It collects information like age, gender, ethnicity, language, and health conditions (e.g., diabetes, blood pressure, cholesterol levels, and medications). Personal details such as names, birthdates, and addresses are removed to keep patient information private.

Lambeth Datanet captures diagnosed sickle cell cases but may undercount true prevalence. Individuals who moved to Lambeth before newborn heel prick screening might not be diagnosed. Newborn screening data offers a more complete picture.

The Black ethnic group in this analysis includes people from Black African, Black Caribbean, and mixed White/Black backgrounds.

Data	Source	Links
Prevalence of sickle cell	Literature / national evidence	• OHID Fingertips • City and Hackney health - Sickle cell • NICE • Sickle cell society
Detected sickle cell	Primary Care	• Lambeth Datanet